

# Assessing the challenges faced by health systems in providing paediatric cotrimoxazole prophylaxis in resource limited countries

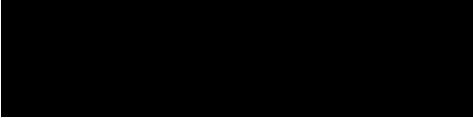
Thesis submitted in fulfilment of the requirements of the University College  
London degree of Doctor of Philosophy (PhD) in Public Health

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### **Author's declaration**

I, Euphemia Lindelwe Sibanda, confirm that the work presented in this thesis is my own.  
Where information has been derived from other sources, I confirm that this has been indicated in the thesis.



## ABSTRACT

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**Introduction:** Cotrimoxazole prophylaxis (CTX-p) is a cost-effective intervention that saves lives of HIV positive individuals. It is recommended by WHO for all infants born to HIV positive women (HIV-exposed infants). Despite this it is poorly implemented in resource-limited countries including Zimbabwe. This project aimed to explore health system and patient-level factors that affect implementation of CTX-p among HIV-exposed infants in Harare, Zimbabwe.

**Methods:** In the first phase of the study, policy and implementation procedures for CTX-p were studied at national and health care centre level through document review and key informant interviews. In the second phase, a detailed study of implementation procedures was conducted at Mbare Clinic, Harare, to explore challenges to CTX-p at various points in the prevention of mother to child transmission (PMTCT) cascade. This involved 1) a survey among post-partum women, 2) qualitative interviews with women who delayed/did not seek antenatal care (ANC), 3) follow-up of HIV positive women at six-weeks postpartum to investigate initiation of CTX-p, and 3) follow-up of HIV-exposed infants until six months to explore adherence. In addition, a systematic review was conducted to investigate the magnitude of loss to follow-up (LTFU) of HIV exposed infants from real-life PMTCT programs.

**Results:** CTX-p is recognised as important by the Zimbabwe Ministry of Health; it has been incorporated into guidelines and treatment procedures for HIV-exposed infants. Health systems face challenges implementing CTX-p due to lack of human resources and poor supply chain management. For women, the first hurdle is seeking ANC, where user fees, fear of HIV testing, unsupportive husbands/partners, nurses' discourteousness and long queues are barriers. Lack of knowledge of the importance of a six-week visit is the main barrier to six-week visit attendance. Adherence challenges include: unsupportive husbands/partners, drug stock-outs and fear of unwanted HIV disclosure and associated stigma. The systematic review revealed that there is unacceptable LTFU of HIV-exposed infants along various points of the PMTCT cascade.

**Conclusion:** Health care systems need to put in place measures to ensure optimum implementation of life-saving interventions and retention of HIV-exposed infants in care.

# TABLE OF CONTENTS

<b>ABSTRACT</b> .....	3
<b>LIST OF TABLES</b> .....	8
<b>LIST OF FIGURES</b> .....	9
<b>LIST OF ABBREVIATIONS</b> .....	10
<b>ACKNOWLEDGEMENTS</b> .....	12
<b>CHAPTER 1: AIM OF THE STUDY</b> .....	14
1.1 Specific objectives .....	14
<b>CHAPTER 2: INTRODUCTION</b> .....	15
2.1 Cotrimoxazole and its importance for HIV disease .....	15
2.2 Recommendations for cotrimoxazole prophylaxis for HIV exposed infants .....	17
2.3 Progress in implementation of cotrimoxazole prophylaxis .....	22
2.4 Barriers to implementation of cotrimoxazole prophylaxis in infants and children .....	23
2.4.1 Barriers in the process of translating evidence into policy .....	23
2.4.2 Barriers related to challenges in operational issues .....	25
2.4.3 Challenges faced in Zimbabwe .....	25
2.4.4 Implications of poor coverage of cotrimoxazole prophylaxis on the wider PMTCT cascade services .....	26
2.5 Structure of the thesis .....	26
2.6 Role of the candidate .....	27
<b>CHAPTER 3: SYSTEMATIC REVIEW</b> .....	28
3.1 Overview .....	28
3.2 Background to the systematic review .....	29
3.2.1 Aim of the systematic review .....	29
3.3 Methods .....	30
3.3.1 Inclusion criteria for publications .....	30
3.3.2 Exclusion criteria .....	30
3.3.3 Search methods .....	30
3.3.4. Selection of eligible papers and additional searches .....	32
3.3.5 Review of eligible papers for quality .....	33
3.3.6 Data extraction .....	35
3.3.7 Synthesis of results .....	35
3.4 Results .....	36
3.4.1 Identification and selection of papers .....	36
3.4.2 Description of eligible papers .....	40
3.4.3 Study findings .....	55
3.5 Discussion .....	63

<b>CHAPTER 4: METHODS</b>	69
4.1 Study Design	69
4.2 Methods for Phase 1	70
4.3 Methods for phase 2	71
4.3.1 Assessment of implementation activities at Mbare Polyclinic	76
4.3.2 Assessment of adherence to cotrimoxazole prophylaxis	79
4.3.3 Preliminary analyses of survey data	80
4.3.4 Incorporation of findings of preliminary analysis into study design	80
4.4 Data analysis methods for phase 1 of the study	84
4.5 Data analysis methods for quantitative data	85
4.5.1 Data quality control and cleaning	85
4.5.2 Analysis methods for patient survey data	86
4.5.3 Data analysis methods for six weeks clinic attendance data	89
4.6 Sample size and justification	89
4.7 Methods for qualitative data collection and analysis	90
4.7.1 Justification for incorporating the qualitative approach	90
4.7.2 Epistemological position	90
4.7.3 Approach to data analysis and justification	91
4.7.4 Detailed methods for qualitative data collection and analysis	91
<b>CHAPTER 5: ANALYSIS OF POLICY AND IMPLEMENTATION PROCEDURES FOR COTRIMOXAZOLE PROPHYLAXIS IN ZIMBABWE</b>	93
5.1 Overview	93
5.2 Results	94
5.2.1 Context	94
5.2.2 Content	101
5.2.3 Process	101
5.3 Short discussion on policy analysis	115
<b>CHAPTER 6: PATIENT SURVEY RESULTS</b>	119
6.1 Overview	119
6.2 Demographic and clinical characteristics of participants	119
6.3 ANC Registration and associated factors	122
6.3.1 Variables selected for multivariable analysis and justifications	126
6.4 Knowledge of HIV status during pregnancy	128
6.4.1 Data on women who had ever been tested for HIV	128
6.4.2 HIV testing of partners	131
6.4.3 Knowledge of HIV Status during Pregnancy	132
6.4.4 HIV Testing Behaviour before Pregnancy	135
6.4.5 Referral for HIV-related care	136

6.4.6 Participants' perception of risk of mother to child transmission of HIV .....	137
6.5 Short discussion of findings.....	138
<b>CHAPTER 7: QUALITATIVE FINDINGS ON BARRIERS TO ANC REGISTRATION.....</b>	<b>140</b>
7.1 Overview.....	140
7.2 Description of maternity services at Mbare Clinic .....	140
7.3 Results of the qualitative study .....	141
7.3.1 User fees are a barrier to ANC registration.....	143
7.3.2 Fear of HIV testing as a barrier to ANC registration .....	147
7.3.3 Nurses' discourteousness as a barrier to ANC registration.....	150
7.3.4 Unsupportive male partners .....	155
7.3.5 Long waiting queues at the clinic .....	158
7.3.6. Unintended pregnancy is a barrier to ANC registration.....	159
7.3.7 Consequences of late registration/non registration .....	160
7.4 Summary of study findings .....	161
<b>CHAPTER 8: ATTENDANCE AT SIX-WEEK POST-NATAL VISIT AT MBARE CLINIC</b>	<b>163</b>
8.1 Overview.....	163
8.2 Results of retrospective study of six-week visit attendance.....	163
8.3 Participant attendance of six-week visit.....	166
8.3.1 Prescription of cotrimoxazole prophylaxis for HIV-exposed infants .....	168
8.4 Qualitative findings on barriers to 6-week visit attendance.....	170
8.4.1 Lack of appreciation of importance of six-week visit.....	170
8.4.2 Distrust of nurses .....	173
8.4.3 HIV care for the participants themselves .....	176
8.5 Short discussion of findings.....	177
<b>CHAPTER 9: QUALITATIVE FINDINGS ON ADHERENCE TO COTRIMOXAZOLE PROPHYLAXIS .....</b>	<b>181</b>
9.1 Overview.....	181
9.2 Description of study participants .....	181
9.3 Interview findings .....	186
9.3.1 Feelings about testing HIV positive.....	186
9.3.2 Adherence to cotrimoxazole prophylaxis for babies.....	194
9.3.3 Other issues affecting the study participants.....	207
9.4 Summary of study findings .....	212
<b>CHAPTER 10: DISCUSSION .....</b>	<b>215</b>
10.1 Overview.....	215
10.2 Summary of study findings .....	215
10.2.1 Systematic review findings .....	215
10.2.2 Policy study findings.....	216

10.2.3 Findings from studies of the cotrimoxazole prophylaxis cascade.....	216
10.3 Discussion of study findings .....	217
10.3.1 Policy findings .....	218
10.3.2 Discussion of findings from the cotrimoxazole care cascade .....	222
10.3.3 HIV care for mothers .....	232
10.3.4 Reflexivity (for qualitative studies) .....	233
10.4 Strengths of the study.....	234
10.5 Limitations of the study .....	235
10.6 Recommendations.....	238
10.6.1 Recommendations to ensure optimum provision of services at health centres.....	238
10.6.2 Recommendations to enable women to take up services along the PMTCT cascade.....	240
REFERENCES .....	242
APPENDICES .....	253
APPENDIX 1: Questionnaire at time of delivery .....	254
APPENDIX 2: Questionnaire at six weeks.....	267
APPENDIX 3: Questionnaire for clinic record study .....	270
APPENDIX 4: In-depth interview guides.....	271
APPENDIX 5: Example of field notes .....	277
APPENDIX 6: Example of interview summary .....	280
APPENDIX 7: Example of analytic memo.....	284
APPENDIX 8: Journal article for the systematic review.....	285

## LIST OF TABLES

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Table 2.1: Extract from WHO guidelines on dosages for paediatric cotrimoxazole prophylaxis .....	19
Table 2.2: Summary of WHO recommended testing approaches.....	20
Table 3.1: Search terms used.....	32
Table 3.2: Description of eligible studies.....	41
Table 3.3: Reported outcomes.....	56
Table 5.1: Cotrimoxazole prophylaxis stakeholder analysis.....	113
Table 5.2: List of challenges identified in the policy study.....	116
Table 6.1: Demographic and clinical characteristics of participants.....	121
Table 6.2: Gestation weeks at time of ANC registration.....	123
Table 6.3: Univariable analysis of association of factors with ANC registration.....	124
Table 6.4: Multivariable analysis of factors associated with ANC registration.....	128
Table 6.5: Univariable analysis of factors associated with knowledge of HIV status during pregnancy.....	133
Table 6.6: Multivariable analysis of factors associated with knowledge of HIV status during pregnancy.....	134
Table 6.7: Time since last HIV tested.....	136
Table 8.1: Participant characteristics and association with six-week visit attendance.....	165
Table 8.2: Multivariable analysis of factors affecting six-week visit attendance.....	165
Table 8.3: Characteristics of interviewed participants.....	170
Table 9.1: Characteristics of interviewed participants.....	182



## LIST OF FIGURES

Fig 2.1: Extract from WHO guidelines on paediatric cotrimoxazole prophylaxis.....	18
Fig 2.2: Trends in the estimated number of children (age 0-14 years) needing and receiving cotrimoxazole in Zimbabwe.....	22
Fig 3.1: Results of literature searches.....	38
Fig 3.2: Selection of eligible papers.....	39
Fig 3.3 Loss to follow-up of HIV positive pregnant women between ANC registration and delivery.....	59
Fig 3.4: Loss to follow-up of infants by age 3 months.....	60
Fig 3.5: LTFU of infants after HIV testing.....	62
Fig. 3.6 Simulation of cumulative LTFU of exposed infants along PMTCT cascade.....	67
Fig 4.1: Summary of phase 2 studies.....	76
Fig 4.2: Flow chart of women participants in the various studies.....	84
Fig 4.3: A model for health policy analysis.....	85
Fig 4.4: Causal diagram used to make decisions on which factors to include in model for multivariable analysis.....	87
Fig 5.1: Distribution of the Zimbabwe population by province.....	94
Fig 5.2: Trends in adult HIV prevalence and incidence in Zimbabwe, 1980-2007.....	98
Fig 5.3: Modelling of trends in annual AIDS deaths of children.....	99
Fig 5.4 Extract from City of Harare website.....	111
Fig 6.1 Where last tested for HIV.....	129
Fig 6.2: HIV status of participants.....	129
Fig 6.3: HIV testing of partners.....	132
Fig 6.4: Motivators for Past HIV Testing.....	135
Fig 8.1: Six-week visit attendance of 31 HIV positive study participants.....	167
Fig 8.2: Reasons why cotrimoxazole was not initiated among women who attended six-week visit.....	169
Fig 9.1: Picture of Matapi Flats in Mbare.....	183
Fig 10.1: WHO guidance on task-shifting in the health sector.....	219
Fig 10.2: A framework for the effects of stigma on maternal, neonatal and child health.....	227

## LIST OF ABBREVIATIONS

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AFASS	Conditions to be met when replacement feeding is given to a baby. These include the availability of safe water and sanitation, assurance of continued supplies and ability to prepare and give the food safely. A-Acceptable; F-Feasible; A-Affordable; S-Sustainable; S-Safe
ANC	Antenatal care
ART	Antiretroviral therapy
ARV	Antiretroviral drug
BRIDH	Beatrice Road Infectious Disease Hospital (Harare, Zimbabwe)
CTX-p	Cotrimoxazole prophylaxis
DALY	Disability-adjusted life-year
DBS	Dried blood spot
DNA	Deoxyribonucleic acid
DNA PCR	Deoxyribonucleic acid polymerase chain reaction
EGPAF	Elizabeth Glazer Paediatric AIDS Foundation
EID	Early infant diagnosis
ELISA	Enzyme-linked immuno sorbent assay
GDP	Gross Domestic Product
HAART	Highly active antiretroviral therapy
ICER	Incremental cost effectiveness ratio
ICRC	International Committee of the Red Cross
LTFU	Loss to follow-up
MDG	Millennium Development Goals
MoHCW	Ministry of Health and Child Welfare (Zimbabwe)
MTCT	Mother to child transmission
NAC	National AIDS Council (Zimbabwe)
NICE	National Institute for Health and Clinical Excellence (UK)
OPHID	Organisation for Public Health Interventions and Development (Zimbabwe)
PMTCT	Prevention of mother to child transmission of HIV

PrI	Predictive Interval
QALY	Quality-adjusted life-year
STROBE	Strengthening the reporting of observational studies in Epidemiology
UNAIDS	Joint United Nations Programme for HIV
UNFPA	United Nations Population Fund
UNGASS	United Nations Declaration of Commitment
UNICEF	United Nations Children's Fund
VCT	Voluntary counselling and testing
WHO	World Health Organisation
ZAPP	Zimbabwe AIDS Prevention Project
ZDHS	Zimbabwe Demographic and Health Survey
ZNASP	Zimbabwe National HIV and AIDS Strategic Plan
ZVITAMBO	Zimbabwe Vitamin A for Mothers and Babies Project

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---

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## **CHAPTER 1: AIM OF THE STUDY**

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The aim of this PhD project was to describe the challenges with provision of HIV services to infants born to HIV positive women (HIV-exposed infants). This was achieved through 1) conducting a systematic review that was aimed at determining the magnitude of loss to follow-up of HIV-exposed infants from real-life PMTCT programs and 2) Conducting a research study that investigated the process of and barriers to provision of cotrimoxazole prophylaxis for HIV-exposed infants at one site in Harare, Zimbabwe, focusing on issues relating to policy, as well as health system and patient-level barriers to initiation and adherence to paediatric cotrimoxazole prophylaxis.

### **1.1 SPECIFIC OBJECTIVES**

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The specific objectives of the systematic review are as follows:

- To determine, for the various stages of the PMTCT cascade, the magnitude of loss to follow-up of HIV-exposed infants enrolled in real-life PMTCT programs
- To describe programme characteristics which are associated with lower rates of infant loss to follow-up

The research project is divided into two phases with the following specific objectives:

#### ***Phase 1***

- To describe the Zimbabwe national policies and processes for the:
  - a. provision of cotrimoxazole prophylaxis for HIV exposed babies
  - b. care of HIV infected women in the pre and post-natal periods

#### ***Phase 2***

- To describe implementation of the national cotrimoxazole guidelines and identify barriers affecting each stage of the implementation process
- To estimate levels of adherence to cotrimoxazole among HIV-exposed infants and describe the factors affecting this adherence
- To describe the care that is given to HIV positive pregnant women from diagnosis of infection to initiation of ART.

## CHAPTER 2: INTRODUCTION

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### 2.1 COTRIMOXAZOLE AND ITS IMPORTANCE FOR HIV DISEASE

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Cotrimoxazole is a cheap antibiotic that is widely available in adult and child formulations. It is composed of two antibiotic drugs, trimethoprim and sulfamethoxazole in a 1:5 ratio. The two drugs work on different parts of the same pathway to inhibit bacterial DNA synthesis, thus preventing the multiplication/growth of bacteria. The drug combination (cotrimoxazole) is recommended for treatment of bacterial infections with susceptible organisms (mainly Gram-positive bacteria). The most common use of cotrimoxazole in children is for first line management of acute respiratory tract infections<sup>1</sup>. It is also used for treatment of diarrhoea, infections of the urinary tract, middle ear and skin and soft tissue infections. Cotrimoxazole also has activity against other organisms besides bacteria: it can be used against fungal infections, e.g. *Pneumocystis jiroveci*, a common human pathogen especially among immunocompromised individuals like AIDS patients. Cotrimoxazole also acts against protozoal infections like toxoplasmosis and isosporiasis.

In HIV disease, cotrimoxazole is mainly recommended as prophylaxis against opportunistic infections, particularly *Pneumocystis jiroveci* infection (it is used to treat the same infection in high doses). Many studies have shown that it reduces HIV-related morbidity and mortality when taken as daily prophylaxis. In a randomised controlled trial among adults in Cote d' Ivoire, there was a higher probability of remaining free of severe disease events (defined as death or hospitalisation for any cause) among HIV infected patients in the cotrimoxazole prophylaxis group than those on placebo<sup>2</sup>. Cotrimoxazole prophylaxis was reported to reduce mortality and hospital admission rates among HIV infected adults with TB in Cote d' Ivoire,<sup>3</sup> South Africa<sup>4</sup> and Zambia<sup>5</sup>, and in Uganda was associated with 46% and 31% reductions in mortality and hospital admission respectively<sup>6</sup>. Among children aged 1-14, a randomised controlled trial in Zambia reported a 43% reduction in mortality in the cotrimoxazole group compared to placebo<sup>7</sup>. More recently, there was demonstration that cotrimoxazole remains important even in the HAART era: cotrimoxazole prophylaxis was associated with reduced mortality when taken alongside antiretroviral therapy in adults, at least up to 72 weeks after starting combination ART<sup>8</sup>. In children a recent trial found that continued cotrimoxazole in children above 3 years who have been on ART for at least 96 weeks is beneficial: children

who stopped cotrimoxazole were more likely to be hospitalised or die, HR 1.57, (95% confidence interval 1.09- 2.26.<sup>9</sup> Thus cotrimoxazole leads to an improvement in the quality of life of the HIV infected person, while at the same time it reduces the burden on the health care system and caregivers.

There is evidence that the beneficial effects of cotrimoxazole prophylaxis are not limited to prevention of opportunistic infections but also include prevention of intercurrent illness due to other infections, most notably acute respiratory tract infection in infants or other common childhood infections.<sup>9 10</sup> Also of note, it has been reported to protect against malaria in both adults and children.<sup>9,11-14</sup> This is very important as malaria is endemic to many countries where HIV prevalence is high. In addition, evidence from the DART trial cohort (a randomised trial of management strategies in HIV-infected, symptomatic, previously untreated adults starting triple drug ART in Zimbabwe and Uganda) indicates that cotrimoxazole may have activity that goes beyond the prevention of intercurrent illness: it may increase and accelerate reductions in immune activation through lowering bacterial load in the gut<sup>8</sup>. This is in support of earlier findings in Uganda where cotrimoxazole prophylaxis was associated with a stabilising effect on immune function as seen in the reduction in annual rate of decline in CD4 cell count and decrease in annual rate of increase in viral load<sup>6</sup>.

Cotrimoxazole prophylaxis has also been found to have favourable outcomes on growth and anaemia in children<sup>15</sup>, an important finding given that HIV infected children in Africa are frequently underweight and stunted. A study in Zambia among HIV infected children who were not on ART showed that cotrimoxazole prophylaxis was associated with at least a two-fold reduction in weight-for-age decrease and a three-fold reduction in height-for-age decrease compared to placebo<sup>15</sup>. The same study also reported a four-fold greater increase in haemoglobin level among those on cotrimoxazole prophylaxis compared to placebo.

Prophylaxis with cotrimoxazole has also been reported to reduce morbidity and mortality among HIV-uninfected family members: In Uganda, over a 22-month period it was associated with 63% reduction of deaths from all causes among family members <10 years old, 38% reduction in malaria incidence among family members, 41% and 43% reductions in incidence of diarrhoea and hospitalisations for any cause among family members, respectively.<sup>16</sup>



There are operational benefits of cotrimoxazole prophylaxis, which include improved retention in follow up of ART ineligible patients in countries where cotrimoxazole is given to individuals regardless of CD4 count in line with WHO guidelines for settings with high infectious disease prevalence. In Kenya, there was improvement in the 12-month retention of ART-ineligible clients following the implementation of the national guidelines on provision of cotrimoxazole prophylaxis to all ART-ineligible clients (84% in the period after vs 63% in the period prior to implementation of the guidelines,  $p < 0.001$ )<sup>17</sup>. Maintaining ART ineligible patients in follow up is vital to ensure timely identification of ART eligibility and subsequent initiation on antiretroviral drugs. Mothers or caregivers may be more likely to bring their babies for HIV testing and follow-up care if they know that an effective treatment is immediately available<sup>18</sup>. This gives the health care system an opportunity to provide HIV-related care to the mother and other family members. In addition, since cotrimoxazole prophylaxis usually precedes ART in resource limited settings, it can provide an opportunity to develop strategies that ensure good adherence to medication, which will become invaluable once ART is initiated.

Although it is generally regarded as a safe drug, the use of cotrimoxazole has associated side effects. It exhibits side effects of the two drug compounds that it is made of. The most common adverse effects of sulfamethoxazole are allergies, fever, skin rashes, photosensitivity, nausea, vomiting, diarrhoea, urinary tract disturbances due to precipitation in urine and blood disorders like anaemia. Trimethoprim also causes blood disorders. Patients with AIDS and *Pneumocystis* pneumonia have a particularly high frequency of adverse reactions to cotrimoxazole, especially fever, rashes, leukopenia and diarrhoea<sup>19</sup>.

## **2.2 RECOMMENDATIONS FOR COTRIMOXAZOLE PROPHYLAXIS FOR HIV EXPOSED INFANTS**

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In 2000 the World Health Organisation (WHO) and Joint United Nations Program for HIV (UNAIDS) recommended cotrimoxazole prophylaxis for all infants born to HIV infected women (HIV exposed children), starting at age six weeks (or first contact with the health care provider) and continuing until HIV infection had been excluded<sup>20</sup>. This was followed by poor implementation in many resource-limited settings, partly because there were no WHO guidelines for national programmes in such settings. In 2006 WHO issued operational recommendations for global implementation of cotrimoxazole prophylaxis among HIV-

exposed children, children living with HIV, and adolescents and adults living with HIV in the context of scaling up HIV care in resource-limited settings<sup>21</sup>. By 2008 there was still sub-optimum implementation (see section 2.3), so WHO issued more guidance on practical approaches to implementation and scale-up, with practical guidance on mechanisms to systematically identify and follow-up HIV-exposed infants at and after birth and on supply chain management.<sup>1</sup> Fig 2.1 below shows the current (2009) WHO guidelines on paediatric cotrimoxazole prophylaxis.

Situation			
HIV-exposed infants and children <sup>a</sup>	Infants and children confirmed to be living with HIV <sup>b</sup>		
	<1 year	1–4 years	≥5 years
Co-trimoxazole prophylaxis is universally indicated, starting at four to six weeks after birth and maintained until risk of HIV transmission ceases and HIV infection is excluded	Co-trimoxazole prophylaxis is indicated regardless of CD4 percentage or clinical status <sup>c</sup>	WHO clinical stages 2, 3 and 4 regardless of CD4 percentage  <b>OR</b> Any WHO stage and CD4 <25%	Follow adult recommendations
<b>OR</b>			
Universal option: prophylaxis for all infants and children born to mothers confirmed to be or suspected of living with HIV. This strategy may be considered in settings with a high prevalence of HIV, high infant mortality due to infectious diseases and limited health infrastructure.			
<p>a. Defined as a child born to a mother living with HIV or a child breastfeeding from a mother living with HIV until HIV exposure stops (six weeks after complete cessation of breastfeeding) and infection can be excluded.</p> <p>b. Among children younger than 18 months, HIV infection can only be confirmed by HIV viral testing.</p> <p>c. Once a child is started on co-trimoxazole, prophylaxis should continue until five years of age regardless of clinical symptoms or CD4 percentage. Specifically, infants who begin co-trimoxazole prophylaxis before the age of one year and are subsequently asymptomatic and/or have CD4 levels ≥25% should remain on co-trimoxazole prophylaxis until they reach the age of five years.</p>			

Fig 2.1: Extract from WHO guidelines on paediatric cotrimoxazole prophylaxis<sup>1</sup>

The Zimbabwe Ministry of Health and Child Welfare adopted the same WHO guidelines for paediatric cotrimoxazole prophylaxis. Initiation of cotrimoxazole prophylaxis is however

only done at the six-week postnatal visit (or later) and there are no guidelines to begin as early as 4 weeks as suggested by the WHO guidelines<sup>22</sup>.

The recommended dosages for cotrimoxazole are as shown in the next table<sup>1</sup>:

**Table 2.1: Extract from WHO guidelines on dosages for paediatric cotrimoxazole prophylaxis**

<b>Recommended daily dosage</b>	<b>Suspension (5ml of syrup 200mg/40mg)</b>	<b>Child tablet (100mg/20mg)</b>	<b>Single strength adult tablet (400mg/80mg)</b>	<b>Double strength adult tablet (800 mg/160mg)</b>
<i>&lt;6 months or &lt;5 kg</i>  100 mg sulfamethoxazole/ 20mg trimethoprim	2.5ml	One tablet mixed with feed or small amount of milk or water	¼ tablet, possibly mixed with feed or small amount of milk or water	-
<i>6 months–5 years or 5–15 kg</i>  200 mg sulfamethoxazole/ 40 mg trimethoprim	5ml	Two tablets	Half-tablet	-
<i>6–14 years or 15–30 kg</i>  400 mg sulfamethoxazole/ 80 mg trimethoprim	10mls	Four tablets	One tablet	Half tablet
<i>&gt;14 years or &gt;30 kg</i>  800 mg sulfamethoxazole/ 160 mg trimethoprim	-	-	Two tablets	One tablet
Frequency once a day				

These are the same dosages that have been adopted by the Zimbabwean Ministry of Health and Child Welfare<sup>22</sup>.

The timely administration of cotrimoxazole prophylaxis requires knowledge of the infant's HIV exposure/infection status. To achieve this WHO also have guidelines for infant/baby testing, table 2.2 below. The guidelines have also been adopted by Zimbabwe<sup>22</sup>.

**Table 2.2: Summary of WHO recommended testing approaches<sup>23</sup>**

Category	Test required	Purpose	Action
Well, HIV-exposed infant	Virological testing at 4-6 weeks of age	To diagnose HIV	Start ART if HIV infected
Infant – unknown HIV exposure	Maternal HIV serological test <b>or</b> Infant HIV serological test	To identify or confirm HIV exposure	Need virological test if HIV-exposed
Well, HIV-exposed infant at 9 months	HIV serological test (at last immunization, usually 9 months)	To identify infants who have persisting HIV antibody or have seroreverted	Those HIV seropositive need virological test and continued follow up; those HIV negative, assume uninfected, repeat testing required if still breastfeeding
Infant or child with signs and symptoms suggestive of HIV	HIV serological test	To confirm exposure	Perform virological test if <18 months of age
Well or sick child seropositive >9 months and <18 months	Virological testing	To diagnose HIV	Reactive start HIV care and ART if under 24 months, or based on national start criteria if 24 months or more
Infant or child who has completely discontinued breastfeeding	Repeat testing six weeks or more after breastfeeding cessation - usually initial HIV serological testing followed by virological testing for HIV-positive child and <18 months of age	To exclude HIV infection after exposure ceases	Infected infants and children <24 months of age, need to start HIV care, including ART

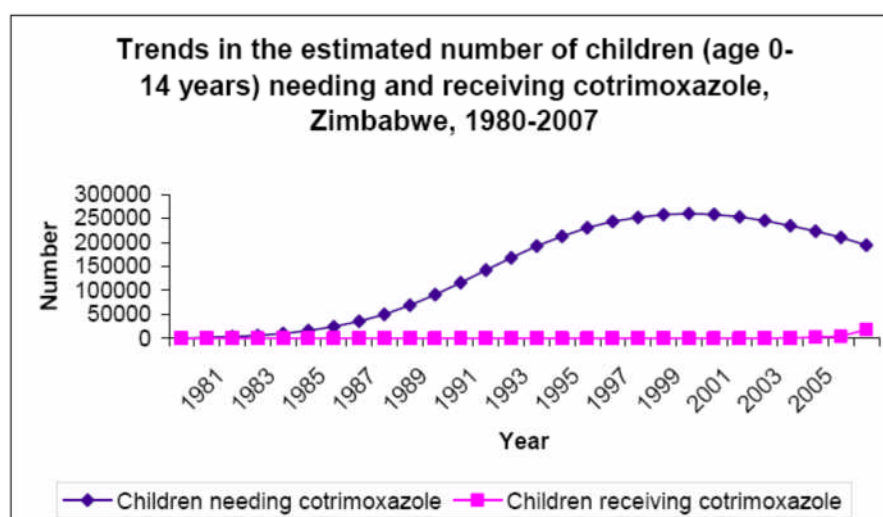
The cotrimoxazole prophylaxis recommendations are important as there is evidence that HIV-exposed infants face more morbidity and death than do those born to HIV uninfected mothers because they are exposed to a greater burden of pathogens. A study in Zimbabwe showed that among HIV infected and uninfected infants who survived to age six months, those born to HIV infected mothers were 16 times more likely to die by 12 months of age compared to those unexposed to HIV<sup>24</sup>. The major cause of death was acute respiratory tract infection. This study not only reinforces the importance of cotrimoxazole prophylaxis for HIV infected infants, but also shows that it is of immense benefit to the uninfected HIV exposed infants, although recent studies have not shown its benefit on non-malarial morbidity for the HIV negative infants.<sup>13,25</sup> The same study<sup>24</sup> demonstrated that infants who are infected during pregnancy or labour are at increased risk of dying in the first 2-6 months of life, which underlies the importance of initiating cotrimoxazole prophylaxis in the first few weeks of life.

The successful roll-out of antiretroviral drugs (ARVs) and PMTCT programmes in resource-rich countries has diminished the importance of cotrimoxazole prophylaxis for HIV-exposed infants in such settings. However, there is recent evidence of continued benefit of cotrimoxazole prophylaxis in children who have been on HAART for more than two years in resource limited countries where there is high prevalence of bacterial and protozoan infections<sup>9</sup>. In addition, in many resource-limited countries the scale-up of ART and PMTCT programmes is still incomplete; hence cotrimoxazole prophylaxis remains vital in the management of HIV disease outcomes. Furthermore, treatment of HIV infected infants is complicated by the limited availability of definitive virological tests for diagnosis of HIV in resource-limited settings. The more widely available, low-cost, rapid HIV test kits, which test for the presence of HIV antibodies, are not appropriate for use in this population because of the persistence of maternal antibodies. Although availability of early infant diagnosis (EID) using DNA PCR has increased in recent years as a result of the introduction of the dried blood spot (DBS) specimen collection on filter paper and PCR testing on these specimens, in many settings the only available option is for health care workers to test only at 18 months with antibody tests<sup>1</sup>. By that age many HIV infected children will have died if no intervention has been made<sup>24</sup>. Fortunately in Zimbabwe EID using DBS on filter paper is now widely available and is the standard of care in the public health system.

## 2.3 PROGRESS IN IMPLEMENTATION OF COTRIMOXAZOLE PROPHYLAXIS

Despite the convincing evidence of effectiveness, widespread recommendations and availability of cotrimoxazole at low cost, the implementation of cotrimoxazole prophylaxis for HIV exposed infants in developing countries has been poor<sup>18,26</sup>. WHO estimated that only 1% of the 4 million children who needed cotrimoxazole were getting it in 2006<sup>27</sup>. In 2008, this figure had only risen to 8%<sup>1</sup>, and to 14% in 2009<sup>28</sup>. In Eastern and Southern Africa, coverage increased from 9% in 2008 to 18% in 2009<sup>28</sup>. In Zimbabwe in 2007, of the 194,000 children aged 0-14 years who needed cotrimoxazole prophylaxis, only 11% received it (figure 2.2)<sup>29</sup>. In three rural Zimbabwean districts where expansion of the national PMTCT program benefits from the technical support of a partner organization (ZVITAMBO), only ~35% of infants known to be HIV-exposed were started on cotrimoxazole prophylaxis in 2007<sup>30</sup>, indicating that an unacceptably high proportion of infants fail to access cotrimoxazole. By 2010, coverage of cotrimoxazole prophylaxis had only increased to 34% in Zimbabwe<sup>31</sup>.

**Fig 2.2: Trends in the estimated number of children (age 0-14 years) needing and receiving cotrimoxazole in Zimbabwe<sup>29</sup>**



## **2.4 BARRIERS TO IMPLEMENTATION OF COTRIMOXAZOLE PROPHYLAXIS IN INFANTS AND CHILDREN**

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There is limited literature on the specific challenges or barriers that each country has faced in rolling-out cotrimoxazole prophylaxis. The barriers summarised below have been reported in reviews and reports, but not as part of detailed case studies.

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### **2.4.1 Barriers in the process of translating evidence into policy**

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The WHO/UNAIDS recommendation for cotrimoxazole prophylaxis among HIV exposed infants issued in 2000 met a lot of resistance from clinicians and policy makers<sup>18,32</sup>. A review by Zachariah et al<sup>18</sup> described some of the policy barriers that prevented the scale up of cotrimoxazole prophylaxis. First, as initial studies that demonstrated the effectiveness of cotrimoxazole were conducted in countries where the prevalence of microbial resistance to cotrimoxazole was low, there was concern that the intervention may not work in areas where resistance to cotrimoxazole is high. Fortunately there is now convincing evidence from Zambia and South Africa that it is effective even in these settings, and indeed the beneficial effects persist even as resistance to cotrimoxazole increases<sup>5,7,33</sup>. Clinicians and policy makers have also worried that blanket use of cotrimoxazole prophylaxis will increase microbial resistance not only to cotrimoxazole, but to other antibiotic classes as well. These fears may be allayed by findings from a recent systematic review that found no evidence of increase in bacterial resistance to antibiotics other than cotrimoxazole as a result of cotrimoxazole prophylaxis<sup>34</sup>.

There were also concerns that cotrimoxazole prophylaxis may not be cost effective. Again this concern can now be allayed by evidence that cotrimoxazole prophylaxis is a highly cost effective intervention<sup>35,36</sup>, with a unit cost of only about US\$0.03 per child per day, or about US\$10/year<sup>27</sup>. In Zambia, cotrimoxazole prophylaxis was associated with incremental cost-effectiveness ratios (ICERs) of US\$72 per life-year saved, US\$94 per QALY saved and US\$53 per DALY averted which is substantially less than the country's cost effectiveness threshold of US\$1,019 per outcome<sup>35</sup>. In comparison, in Sub Saharan Africa the average cost per DALY averted for first-line antiretroviral therapy without intensive monitoring is \$556 (international dollars)<sup>37</sup>.

More recently, some clinicians and researchers have called for a review of the cotrimoxazole prophylaxis guidelines to stop blanket cotrimoxazole prophylaxis as there have been improvements in the following areas: PMTCT coverage, ARV prophylaxis for infants born to HIV positive mothers and early infant diagnosis through dried blood spot testing<sup>38</sup>. They argue that it no longer makes sense to roll-out cotrimoxazole prophylaxis to all HIV exposed infants because the majority of them have been prevented from acquiring HIV from their mothers. However, current data show that there is still incomplete roll-out of programmes aimed at reducing transmission of HIV from mothers to their children. In 2009, coverage for ARVs for preventing mother-to-child transmission was at 54% in sub-Saharan Africa, although it was higher (68%) in Eastern and Southern Africa<sup>28</sup>. By 2010 the coverage for PMTCT ARVs had increased slightly in Sub-Saharan Africa to 60% (50% received most effective PMTCT regimens and 10% received single dose nevirapine, which is no longer recommended)<sup>39</sup>. In 2009, 35% of HIV exposed infants received ARV prophylaxis in sub-Saharan Africa (45% in Eastern and Southern Africa); in 2010 this increased to 43% in Sub-Saharan Africa and 55% in Eastern and Southern Africa. Early infant diagnosis still remained a challenge, with WHO/UNAIDS/UNICEF reporting that in 2009 only 6% (5-10%) of infants were tested for HIV within the first two months of birth in low-and medium-income countries; this had increased to 28% in 2010.<sup>28,39</sup> Given these limitations it still makes sense to roll-out cotrimoxazole prophylaxis to all HIV exposed infants, particularly in those settings where PMTCT and early infant diagnosis coverage is low.

Despite this compelling evidence of effectiveness and assurances on potential fears, this has resulted in little improvement in rates of implementation: more barriers need to be overcome. A study of the processes for national policy development on cotrimoxazole prophylaxis in Malawi, Uganda and Zambia showed that the availability and widespread dissemination of results did not necessarily result in translation of research into policy, but that the context (including the influence of donor agencies) was important in the adoption of the policy on cotrimoxazole prophylaxis. In addition, the nature of the evidence played a significant role: in all three countries the policy makers believed that the preliminary WHO recommendations in 2000 were based on weak evidence, where the main deterrent was fear that cotrimoxazole prophylaxis would not be effective in settings of high microbial resistance to cotrimoxazole as described at the beginning of this section. Other factors that were found to be important were links between researcher, policy makers and those seeking to influence the policy process.<sup>40,41</sup>



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### 2.4.2 Barriers related to challenges in operational issues

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Even after the adoption and formulation of cotrimoxazole prophylaxis policies, challenges are faced in translating policy into practice. There was delay in getting policy guidance on how cotrimoxazole prophylaxis should be implemented as initial guidelines on HIV/AIDS focused on antiretroviral drugs for treatment and PMTCT.<sup>1,18</sup> Since 2006 WHO have been producing guidelines for the implementation of cotrimoxazole prophylaxis in infants and children.<sup>1,18,21</sup> Many health care services do not have in place processes for the identification of all infants or children who are eligible for cotrimoxazole prophylaxis.<sup>1,18</sup> In addition, shortages of trained staff and stock-outs of cotrimoxazole have resulted in suboptimal scale-up of the intervention<sup>1,18</sup>.

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### 2.4.3 Challenges faced in Zimbabwe

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There is no published literature on the specific challenges that the Zimbabwean health services face in scaling-up cotrimoxazole for HIV exposed infants. Despite a recent well documented decline in HIV prevalence<sup>42</sup> to 15%<sup>43</sup>, Zimbabwe still has one of the most severe HIV epidemics globally. It was estimated in 2009 that 9,400 children aged 0-14 died of AIDS; representing 14% of total annual AIDS deaths. It is therefore of paramount importance to explore why only 11% of children who needed cotrimoxazole prophylaxis were getting it in 2007, and why this had only increased to 34% in 2010. In addition, the high rates of loss to follow-up of HIV exposed infants implies that their mothers are also not engaged in HIV-related care and will not be assessed for ART eligibility on time and will thus not have good health outcomes.

More generally, the issue of effective implementation of pharmaceutical interventions is becoming an increasingly important issue in resource limited settings as ARV treatment becomes more widely available. Drug delivery mechanisms that were established when WHO's 3 by 5 Programme was launched ten years ago may not be able to cope with the rapid scale up that is required. As outlined by the International Network for Rational Use of Drugs ([www.INRUD.org](http://www.INRUD.org)) being able to monitor implementation and adherence to HIV drug interventions is crucial to their successful scale up.

In the study outlined here, information was collected to identify the barriers to effective cotrimoxazole implementation among infants born to HIV infected women. Many of the

findings of this research will likely be generalisable to other resource poor settings. In addition it is likely that some aspects of the research methodology will be adapted and used to evaluate rollout of other pharmaceutical interventions (e.g. ARVs or isoniazid prophylaxis).

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#### **2.4.4 Implications of poor coverage of cotrimoxazole prophylaxis on the wider PMTCT cascade services**

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Poor coverage of cotrimoxazole prophylaxis will result in unnecessary morbidity and mortality among HIV-exposed infants. It might mean that health care workers failed to prescribe cotrimoxazole prophylaxis, or that cotrimoxazole was out of stock, or more critically, that infants have been lost to follow-up from the PMTCT cascade. In the next chapter, I present results of a systematic review which explores the extent of and factors associated with loss to follow-up of HIV-exposed infants from PMTCT programmes globally. The data combined with locally generated data on facilitators and barriers to cotrimoxazole prophylaxis implementation can be used to inform future program and policy development.

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## **2.5 STRUCTURE OF THE THESIS**

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The thesis is divided into ten chapters. The objectives of the study are given in Chapter 1. In this chapter there is discussion of the importance of paediatric cotrimoxazole prophylaxis, challenges in implementation and the rationale for conducting the study. In the third chapter I describe a systematic review I conducted to investigate the magnitude of loss to follow-up of HIV-exposed infants from real-life PMTCT programs. The methods are described in Chapter 4. Results are presented in Chapters 5-9. In Chapter 5 I present policy findings related to paediatric cotrimoxazole. Chapters 6 to 9 describe results at specific steps on the cotrimoxazole prophylaxis care cascade: identification of infant HIV exposure status (Chapter 6), qualitative findings on barriers to antenatal care (Chapter 7), initiation of cotrimoxazole prophylaxis among HIV exposed infants at six weeks of age (Chapter 8), and experiences with adherence to cotrimoxazole prophylaxis (Chapter 9). All results chapters have short discussions at the end, and the final discussion of all findings with recommendations is made in Chapter 10.

## **2.6 ROLE OF THE CANDIDATE**

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Under the supervision of the primary supervisor, Dr Frances Cowan, and with input from Professor Ian Weller, the candidate designed the study project and submitted it for funding by Wellcome Trust as part of a Masters Fellowship Programme. The candidate was awarded the fellowship, which was later upgraded to a PhD fellowship. The candidate designed the data collection tools and trained the study nurse who collected the bulk of the quantitative data (the candidate administered some of the questionnaires). All qualitative data collection (in-depth interviews) was done by the candidate. All quantitative and qualitative analyses were done by the candidate. Under supervision from the primary supervisor the candidate designed the systematic review, designed the search strategy, implemented the search, identified eligible papers and did all analyses and write-up of the systematic review

## **CHAPTER 3: SYSTEMATIC REVIEW**

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### **3.1 OVERVIEW**

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In this chapter I describe the results of a systematic literature review that I conducted to determine the extent of loss to follow-up of HIV-exposed infants and children from the PMTCT continuum of care. Although the focus of this PhD is on resource-limited settings, the literature review was not restricted to such settings because I wanted to look at some programme characteristics in high income countries that might be responsible for the differences in retention rates. Nevertheless, due recognition was taken of the inherent differences in the health care systems in different parts of the world: during synthesis of results only studies that were conducted in Sub-Saharan Africa were included in the meta analyses.

Publications were eligible for review if they reported on loss to follow-up of infants from standard/routine PMTCT programs, rather than from intervention studies. Literature searches were conducted in Medline, Embase, Web of Knowledge, Maternity and Infant Care and CINAHL Plus. Eligible studies were subjected to quality assessments using checklists that were adapted from the UK National Institute for Health and Clinical Excellence (NICE) methodology checklist for cohort studies. Information extracted from publications included the following: programme years and year of publication, country of study, setting (whether urban or rural), method of offering HIV testing (whether opt-in or opt-out) methods of follow-up of infants including follow-up schedule, PMTCT regimens for mothers and infants, and whether replacement feeding was freely offered at the programme site/s during the reported years. The outcome extracted was the percentage loss to follow-up of infants at any point along the PMTCT cascade. Random effects meta-analyses were done to find the pooled estimates of percentage loss to follow-up at various stages of the PMTCT cascade. Because of the significant heterogeneity in study findings, predictive intervals PrI, (approximate 95% confidence intervals of a future study based on the observed heterogeneity) were calculated. Meta-regression analysis was done to investigate the heterogeneity between the program findings. Analysis was done using Stata version 10.

## 3.2 BACKGROUND TO THE SYSTEMATIC REVIEW

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As described in Chapter 1, implementation of cotrimoxazole prophylaxis among HIV-exposed infants in many resource-limited settings is sub-optimum. Poor implementation of cotrimoxazole prophylaxis points to poor retention of HIV-exposed infants in HIV-related care. This attrition results in failure to access not only cotrimoxazole prophylaxis, but other life-saving interventions as well. For example, current WHO guidelines recommend HIV testing of infants at 4-6 weeks<sup>23</sup> post-natally (early infant diagnosis, EID), and immediate initiation on ART for those testing positive. As early cessation of breastfeeding is associated with poor health outcomes for HIV-exposed babies<sup>44-48</sup>, current guidelines support continued breastfeeding with extended infant prophylaxis with nevirapine (WHO option A)<sup>49</sup>, and re-testing of the exposed baby at least six weeks after cessation of breastfeeding<sup>23</sup>. These guidelines necessitate continued follow-up of exposed babies to provide the continuum of care. Yet despite the advances in knowledge of effective interventions to save the lives of HIV exposed infants, many infants do not access the full package of services because of loss to follow-up<sup>50-53</sup>. There is literature on loss to follow up of infants in research settings, and also in real-life programme settings. This systematic review is being conducted in order to determine the magnitude of loss to follow-up of HIV-exposed infants from real-life (non-research intervention) PMTCT programs. This is important in order to gauge the real world experience of implementing current interventions and inform future program and policy development.

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### 3.2.1 Aim of the systematic review

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The overall aim of the systematic review is to determine the magnitude of loss to follow-up of HIV-exposed infants from real-life PMTCT programs in order to inform programmers and policy-makers about the progress made and likely interventions for improving retention.

#### Specific objectives

1. To determine, for the various stages of the PMTCT cascade, the magnitude of loss to follow-up of HIV-exposed infants enrolled in real-life PMTCT programs
2. To describe programme characteristics which are associated with lower rates of infant loss to follow-up

### 3.3 METHODS

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#### 3.3.1 Inclusion criteria for publications

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Publications were eligible for inclusion if they met all of the following criteria:

- i) **Population:** Children or infants born to HIV positive women. The infants could be HIV infected, uninfected or of unknown HIV status.
- ii) **Intervention:** The infants/children or mother-infant pairs had to be enrolled in a programme for usual or standard care for HIV positive women and their infants in their setting. This could be a PMTCT programme, or any programme that was publicly set up to provide care for HIV-exposed or infected children rather than as intervention research studies.
- iii) **Outcome:** Studies should have reported on retention or loss to follow-up of HIV-exposed infants.
- iv) **Study design:** Longitudinal studies; i.e. publications had to report on programmes that longitudinally followed HIV exposed infants. Data collection could be prospective or retrospective.
- v) Publications had to be in **English** (for practical reasons due to unavailability of funds that could be used for any translation work), and must have been **published** in peer reviewed journals.

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#### 3.3.2 Exclusion criteria

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Publications were excluded if the setting was not considered routine or standard of care for that community.

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#### 3.3.3 Search methods

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##### 3.3.3.1 Databases searched

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The following databases were searched:

- i) Medline: accessed on 06 August 2012.
- ii) Embase: accessed on 06 August 2012.
- iii) Web of knowledge: accessed on 06 August 2012.
- iv) CINAHL Plus: accessed on 06 August 2012.
- v) Maternity and infant care: accessed on 06 August 2012.

All the databases were selected because of their relevance to the systematic review topic. Medline and Embase were selected because they both have wide international coverage of clinical and biomedical research findings and were therefore highly likely to have publications on the systematic review topic. Web of knowledge was also selected because of its wide subject coverage but more specifically for its usefulness in reference and citation searches. Maternity and Infant Care was chosen because its focus is closely related to the topic of this systematic review. CINAHL Plus was chosen because of its focus on nursing and allied health topics, including biomedicine.

### **3.3.3.2 Search strategy**

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The research question was split into three components: 1) children or infants, 2) HIV exposure, and 3) retention/loss to follow-up. Literature covering this topic was read in order to identify synonyms that are normally used in the subject. For each component, text searches in the databases using identified synonyms were carried out. To ensure inclusiveness of text searches, truncation of word endings was done. In addition there was allowance for various ways of adjacency for words in a phrase, see table 3.1 below. Medical Subject Headings (MeSH) were used in addition to text searches for Medline, Embase and Maternity and Infant Care. In each database, for each component, the results of the text searches and MeSH heading searches (where applicable) were combined using the Boolean operator “OR” in order to include all papers that related to the component. Results from the three components were then brought together using the operator “AND”, which narrowed the search to include only the publications which featured all the three components of the research question (see table 3.1 below).

The search process was iterative: pilot searches using the above method were done and checks for the suitability of the search terms were done by looking at whether the search identified papers which were already known to be eligible for review. Refinements of the search terms were made and the final search terms were run in all the databases on 06 August 2012.

The search terms and strategy were discussed with a librarian at UCL Cruciform Library.

**Table 3.1: Search terms used**

Concept 1: HIV exposure	Concept 2: Retention/LTFU	Concept 3: Child/Infant
HIV exposed	Continuum of care	Child* OR infant* OR newborn OR baby OR babies
HIV positive adj3 mother*	Retention OR attrition OR "patient dropout" OR "los? to follow up" OR LTFU OR LFU OR "lost follow up"	MeSH terms specific to each database as applicable
HIV infected adj3 mother*	Early infant diagnosis or EID	<b>All the above terms were combined with operator “OR”</b>
born adj3 HIV positive wom#n	MeSH terms specific to each database as applicable	
born adj3 HIV infected wom#n).	<b>All the above terms were combined with operator “OR”</b>	
PMTCT OR "prevention of mother to child transmission"		
MeSH terms specific to each database as applicable		
<b>All the above terms were combined with operator “OR”</b>		
Results from Concept 1, Concept 2 and Concept 3 were brought together using the operator “AND”		

adj3 means the two terms are within three words of each other

\* is a truncation sign

# allows for different spelling/words; in this case will capture both 'woman' and 'women'

### 3.3.4. Selection of eligible papers and additional searches

The papers that were identified from each of the databases were uploaded into a single file (or library) in the Endnote reference management software. Duplicates were identified and removed. The endnote file (which had all the titles and abstracts, where available) of the identified papers was then printed. Each title and abstract was carefully reviewed to determine whether the paper met the study inclusion criteria. Where it was obvious that the paper was not eligible based on title and abstract review, the paper was deemed ineligible, and this was documented against the specific paper on the printed document. Where it was less clear from the title and abstract review whether the paper was eligible, the full paper was reviewed. If the full paper was deemed ineligible the reasons for rejection were documented i.e. it was documented which of the inclusion criteria the paper had failed to meet.



The reference and citation lists of papers which were deemed to be eligible for review, and those of other relevant papers which published on the subject of the review, were downloaded to another Endnote library using the Web of Knowledge database. This library was integrated with that of the general database search, duplicates were removed and a review of the additional papers identified through reference and citation lists was done.

The review for eligibility was done by the candidate.

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### **3.3.5 Review of eligible papers for quality**

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Each eligible publication was assessed for quality of reporting and quality of the study. The assessment was made using a checklist that was adapted from the UK National Institute for Health and Clinical Excellence (NICE) methodology checklist for cohort studies<sup>54</sup>. In developing the checklist, careful reference was also made to other popular guidelines that have been published on quality reporting of observational longitudinal studies, e.g. criteria published by Tooth et al<sup>55</sup> and The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE statement).<sup>56-64</sup> Of note, as the outcome of interest in this review was retention or loss to follow up, which was not the main outcome of interest in most papers, many NICE criteria which related to analysis methods or effect estimates were not applicable. The checklist that was used after disregarding the inapplicable criteria is shown in the next page.

Checklist for quality assessment (adapted from UK NICE Guidelines<sup>54</sup>)**Author & date:**

Quality criterion	Well covered	Adequately addressed	Poorly addressed	Not addressed	Not reported	N/A	Comments
1. Are the objectives or hypotheses of the study stated?							
2. Is the target population defined?							
3. Is the sampling frame defined?							
4. Is the study population defined?							
5. Are the study setting (venues) and/or geographic location stated?							
6. Are the dates between which the study was conducted stated or implicit?							
7. Are the eligibility criteria stated?							
8. Are the issues of 'selection in' to the study mentioned?							
9. Are the numbers of participants justified?							
10. Was the number of participants at the beginning of the study stated?							
11. Were the methods of data collection stated?							
12. Was the reliability (repeatability) of measurement methods mentioned?							
13. Are the methods of follow-up given?							
14. Was the number of participants at each stage/wave specified?							
15. Were the reasons for loss to follow-up quantified?							
16. Was the missingness of data items at each wave mentioned?							
17. Were missing data accounted for in the analyses?							
18. Was the impact of biases estimated quantitatively or qualitatively?							
19. Was there any other discussion of generalizability?							
20. Overall assessment of the study (good quality; fair quality; poor quality) and comments							

For each study, an overall subjective judgement was made on how well the findings of the study were protected against bias and confounding. Studies were judged as good, fair or poor. The following criteria were used for the judgement:

**Good-** if the study met all or most quality criteria as detailed in the quality assessment tools. Where some criteria were not met the study would only be judged as good if findings of the study were unlikely to alter if the criteria were met.

**Fair-**Some of the criteria were met; those criteria that have not been met are thought unlikely to affect the conclusions; findings were thought unlikely to be biased.

**Poor-**Few criteria met or important criteria which are thought very likely to change the conclusion when met have not been met; the reported findings were thought to be significantly biased.

In summary the studies were not judged according to how many criteria they met but according to whether the conclusions of the study were likely to change if the unmet criteria applied.

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### 3.3.6 Data extraction

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Data were extracted using a data collection form which captured the following information where reported: place of study including name of study sites, setting (urban or rural), programme years covered by the report, stage at which antenatal care was sought, testing strategy at the site (whether opt-in or opt-out), schedule and methods of follow-up of infants, PMTCT regimens offered to mothers and their babies, whether replacement feeding was freely given at the site during the years studied, study quality, and finally magnitude and timing of loss to follow-up. To avoid data extraction errors, after data had been extracted from all papers a quality control check was done where each paper was re-read to verify that the captured information was correct.

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### 3.3.7 Synthesis of results

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The findings of the studies were split into categories relating to timing of loss to follow-up as follows: 1) loss to follow-up of pregnant HIV positive women between ANC registration and

delivery; 2) loss to follow-up of HIV-exposed infants by age 3 months; 3) loss to follow-up of HIV-exposed infants by age 12 months and by age 18 months, and 4) loss to follow-up of infants after determination of HIV status but before enrolment into ART programs. For studies that were conducted in Sub-Saharan African countries, random-effects meta-analysis using the method of DerSimonian and Laird<sup>65</sup> was conducted for each category/timing of loss to follow up using the ‘metan’ command in Stata version 10, after supplying the reported proportion and lower and upper limits of the confidence intervals of the loss to follow up data. As confidence intervals were not typically reported in the study results, they were computed for all the studies. To increase the normality of the distribution of the proportion data, data values were log-transformed (natural logarithms) before analysis and the results back-transformed to percentages. During the analysis it was clear that there was extensive heterogeneity of study findings. Because it is not recommended to only report pooled estimates in the presence of significant heterogeneity<sup>66</sup>, predictive intervals, PrI, (approximate 95% confidence intervals of a future study based on the observed heterogeneity) were computed and reported together with the pooled estimates.

To investigate the source of the heterogeneity in studies, random-effects meta-regression analysis using the metareg command in Stata<sup>67</sup> was done with each of the extracted variables that were suspected to explain the heterogeneity: setting (urban/rural), strategy for offering HIV testing (opt-in/opt out); mother’s PMTCT regimen (single dose nevirapine vs. more intensive regimens); and whether replacement feeding was offered for free during the programme years.

In the synthesis of results, all studies were included in the primary analyses; additional analyses were conducted without the poor quality studies.

### 3.4 RESULTS

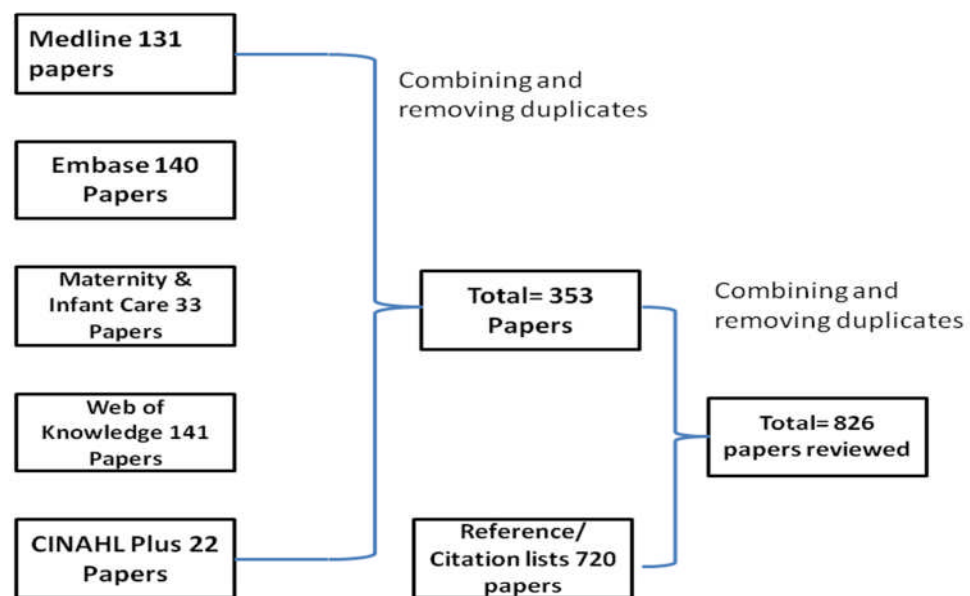
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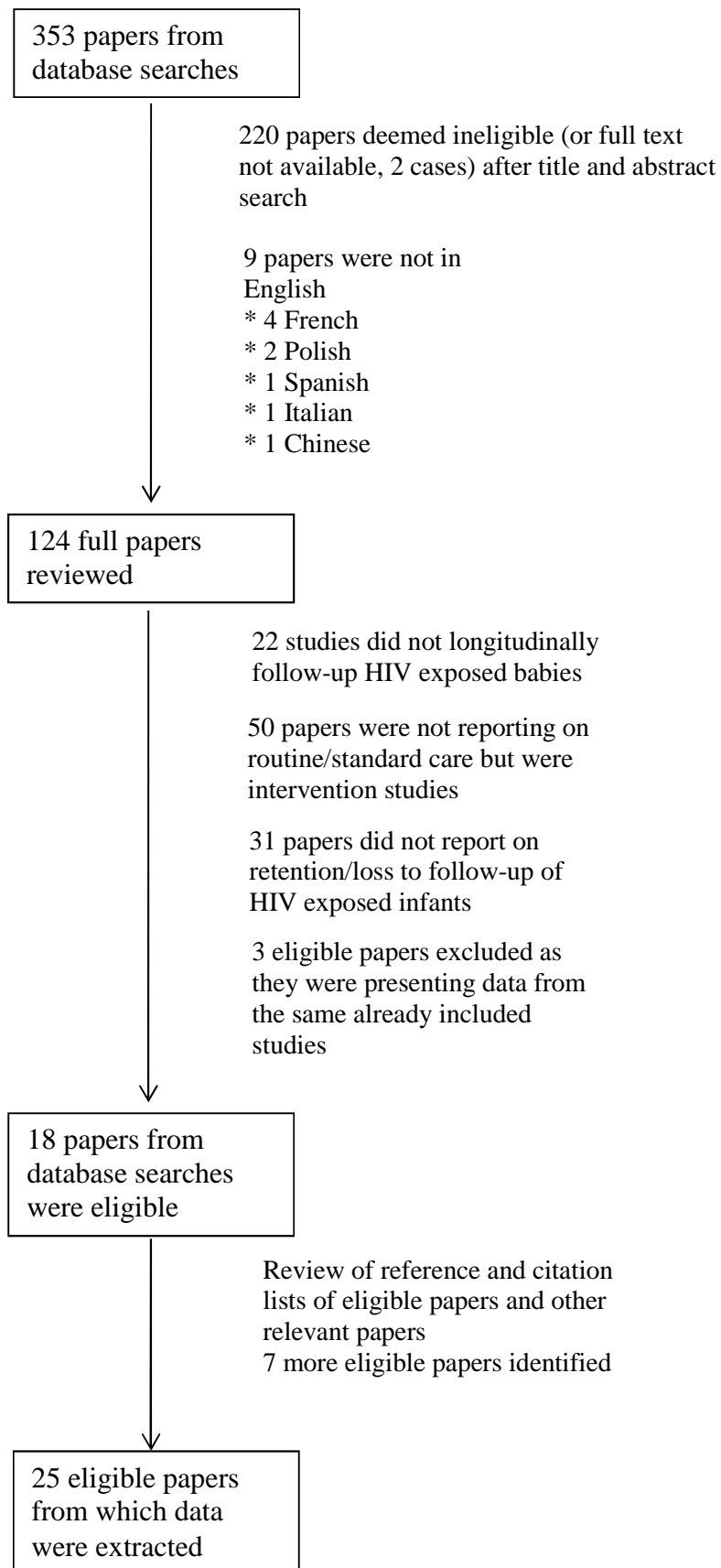
#### 3.4.1 Identification and selection of papers

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A total of 826 papers from database and reference/citation lists were reviewed, see Fig 3.1. 18 eligible papers were identified from database searches, and an additional 7 were identified after reviewing reference and citation lists, bringing the total of eligible papers from which data were extracted to 25 (see figure 3.2 below). Fig 3.2 details the selection process for the

353 papers that were identified during the database searches; it does not include the selection process for reference and citation lists because the reference and citation lists are not as selective as the database searches, they have a much greater proportion of papers that are not relevant to the search. As a result it is usual practise to record the selection process for the database searches and to only state how many papers from the reference and citation lists were found to be eligible for review.

**Fig 3.1: Results of literature searches**

**FIG 3.2: Selection of eligible papers**

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### 3.4.2 Description of eligible papers

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20 studies were from sub-Saharan Africa: four<sup>68-71</sup> from South Africa, two each from Kenya<sup>72,73</sup>, Nigeria<sup>74,75</sup>, Mozambique<sup>76,77</sup>, Malawi<sup>78,79</sup>, Uganda<sup>80,81</sup> and Ethiopia<sup>82,83</sup>, one from each of the following: Zimbabwe<sup>84</sup>, Cameroon<sup>85</sup>, Angola<sup>86</sup>, and Tanzania<sup>87</sup>. Three studies were from India<sup>88-90</sup>, and one each from United Kingdom and Ireland.<sup>91,92</sup> See table 3.2 for a description of the studies. All studies were viewed as either good (17 studies) or fair (eight studies) quality, as a result they were all included in results syntheses as applicable. Seven studies were set in rural areas, 14 in urban areas and three included both urban and rural sites. The PMTCT regimen provided for mothers during the study period was single dose nevirapine for nine studies and was more intensive (i.e. dual or triple therapy or even initiation of HAART) for 13 studies. The model for offering HIV testing was reported in 16 publications; five studies reported that an opt-in strategy was predominantly practised during the study period, for seven it was opt-out and in four studies opt-in was initially offered and opt-out was introduced as the programme progressed.



Table 3.2: Description of eligible studies

Author & Year	City & Country	Description of programme	Programme years	Study quality
Perez et al 2004 <sup>84</sup>	Buhera; Zimbabwe	<b>Setting:</b> Semi-Rural <b>Study site/s:</b> Murambinda Mission Hospital and 27 satellite clinics. <b>Stage at which ANC sought:</b> Not reported <b>ANC testing strategy:</b> Opt-in <b>Follow-up schedule:</b> HIV positive women and babies were followed up at 6weeks postnatally, then monthly for growth monitoring until age18 months. The baby was tested for HIV at 15 months. Follow-up was only done at hospital level. <b>PMTCT Regimen for mother:</b> Single dose nevirapine <b>PMTCT regimen for infant:</b> Single dose nevirapine <b>Whether replacement feeding freely offered:</b> No <b>Other:</b> This was a pilot PMTCT programme; first site to offer PMTCT in Zimbabwe	Aug 2001 to Jan 2003	Good
Nlend et al 2012 <sup>85</sup>	Yaonde, Cameroon	<b>Setting:</b> Urban <b>Study site/s:</b> 25 facilities in the Djoungolo Health District PMTCT programme. <b>Stage at which ANC sought:</b> Not reported <b>ANC testing strategy:</b> PITC (opt-out) <b>Follow-up schedule:</b> Early infant diagnosis at 6 weeks, done at a referral centre <b>PMTCT Regimen for Mother:</b> HAART for eligible women. Those not eligible were given dual therapy with zidovudine and single dose nevirapine <b>PMTCT regimen for infant:</b> Nevirapine syrup for 1 week or 1 month depending on length of maternal treatment <b>Whether replacement feeding freely offered:</b> Not clear <b>Other:</b> CD4 testing given at same site for HIV positive clients. There was patient follow-up using mobile phones (90% of women had mobile phones)	March 2008 to March 2010	Fair  Possibility of misclassification bias

Author & Year	City & Country	Description of programme	Programme years	Study quality
Moses et al 2008 <sup>79</sup>	Lilongwe. Malawi	<b>Setting:</b> Urban <b>Study site/s:</b> Maternity hospital in Lilongwe, and three District health centres in Kawale and Areas 18 & 25 <b>Stage at which ANC sought:</b> Not reported <b>ANC testing strategy:</b> Between April 2002 and July 2003, opt-in; test using ELISA, results collected 1-2 weeks later. Rapid testing from Jul 2003. <i>Opt-out</i> introduced in 2005 <b>Follow-up schedule:</b> Infants were tested using DNA PCR at six weeks (ELISA was used at 18 months). <b>PMTCT Regimen for Mother:</b> Single dose nevirapine <b>PMTCT regimen for infant:</b> Single dose nevirapine <b>Whether replacement feeding freely offered:</b> Not reported	April 2002 to December 2006	Fair
Lussiana et al 2012 <sup>86</sup>	Luanda, Angola	<b>Setting:</b> Urban <b>Study site/s:</b> General population hospital, Municipal Hospital Divina Providencia <b>Stage at which ANC sought:</b> Not reported <b>ANC testing strategy:</b> Not reported <b>Follow-up schedule:</b> HIV testing of infants using rapid tests at 9, 12 and 18 months. Infants are followed on a monthly basis until 24 months of age. <b>PMTCT Regimen for Mother:</b> Immediate ART for eligible women. If not eligible ART is started in third trimester (stopped after delivery if not indicated unless baby is breastfeeding) <b>PMTCT regimen for infant:</b> Zidovudine for four weeks for infants of late-presenting mothers <b>Whether replacement feeding freely offered:</b> Yes <b>Other:</b> A retrospective analysis of hospital records	March 2007 to June 2011.	Good

Author & Year	City & Country	Description of programme	Programme years	Study quality
Geddes et al 2011 <sup>70</sup>	Durban, South Africa	<p><b>Setting:</b> Urban</p> <p><b>Study site/s:</b> McCord Hospital, a state-aided general hospital in Durban</p> <p><b>Stage at which ANC sought:</b> Not reported</p> <p><b>ANC testing strategy:</b> Opt-out since 2006</p> <p><b>Follow-up schedule:</b> Babies were brought to the HIV clinic at the hospital for HIV testing by PCR at six weeks. HIV positive babies were managed at the same HIV clinic, and HIV negative babies were referred to government immunization clinics.</p> <p><b>PMTCT Regimen for Mother:</b> HAART for eligible women. Up to May 2005, single dose nevirapine, dual or triple therapy depending on woman's ability to pay. Thereafter funds were secured for all women for dual and triple therapy (depending on viral load).</p> <p><b>PMTCT regimen for infant:</b> Single dose nevirapine and zidovudine for one week</p> <p><b>Whether replacement feeding freely offered:</b> Not reported</p> <p><b>Other:</b> User fees were paid at each ANC and postnatal visit. A retrospective cohort design</p>	March 2004 to February 2007	Good (although probably not generalizable to South African public institutions)
Doherty et al 2005 <sup>69</sup>	18 sites across all nine provinces in South Africa	<p><b>Setting:</b> Equal representation of rural and urban sites</p> <p><b>Study site/s:</b> 18 sites, two in each of the nine provinces. Purposively selected to have representation of first level and second level facilities</p> <p><b>Stage at which ANC sought:</b> Not reported</p> <p><b>ANC testing strategy :</b> Predominantly opt-in</p> <p><b>Follow-up schedule:</b> Infants were to be followed up for testing using a rapid HIV test kit at 12 months of age. Babies who tested HIV positive at 12 months were to be followed up for re-testing at 18 months.</p> <p><b>PMTCT Regimen for Mother:</b> Single dose nevirapine</p> <p><b>PMTCT regimen for infant:</b> Single dose nevirapine</p> <p><b>Whether replacement feeding freely offered:</b> Freely given to women who opted for it</p> <p><b>Other:</b> This was an evaluation of the pilot PMTCT programme in South Africa.</p>	January 2002 to December 2002	Good

Author & Year	City & Country	Description of programme	Programme years	Study quality
Azcoaga-Lorenzo et al 2011 <sup>72</sup>	Busia District, Kenya	<p><b>Setting:</b> Rural</p> <p><b>Study site/s:</b> 11 Health care centres including 3 dispensaries, five health centres, two sub-district hospitals and one mission hospital.</p> <p><b>Stage at which ANC sought:</b> Not reported</p> <p><b>ANC testing strategy:</b> Opt-out</p> <p><b>Follow-up schedule:</b> HIV exposed babies were tested twice, at six weeks (or as soon as possible afterwards), and if negative again at least six weeks after cessation of breastfeeding.</p> <p><b>PMTCT Regimen for Mother:</b> In three health centres eligible women were started on HAART. In the rest of the sites the standard of care was short course zidovudine plus single dose nevirapine.</p> <p><b>PMTCT regimen for infant:</b> Zidovudine</p> <p><b>Whether replacement feeding freely offered:</b> Not provided</p> <p><b>Other:</b> The Ministry of Health PMTCT programme in this district was supported by MSF which improved decentralisation of the PMTCT services within the district and supported integration of PMTCT activities with ANC.</p> <p>Data were prospectively collected.</p>	01 January 2006 to 31 December 2008	Good

Author & Year	City & Country	Description of programme	Programme years	Study quality
Ahoua et al 2010 <sup>80</sup>	Arua, a rural region in North-Western Uganda	<p><b>Setting:</b> Rural</p> <p><b>Study site/s:</b> Arua Regional Referral Hospital</p> <p><b>Stage at which ANC sought:</b> 233 of 327 (71.3%) enrolled during third trimester of pregnancy</p> <p><b>ANC testing strategy:</b> Opt-in</p> <p><b>Follow-up schedule:</b> Mother-infant pairs were followed at week 1, 6, 10 and 14, and every three months up to 18 months post-partum. Infants were tested for HIV at 18 months using two rapid HIV test kits.</p> <p><b>PMTCT Regimen for Mother:</b> Short course zidovudine from 36 weeks of pregnancy or single dose nevirapine. ART for eligible women.</p> <p><b>PMTCT regimen for infant:</b> Zidovudine for one week or single dose nevirapine</p> <p><b>Whether replacement feeding freely offered:</b> Freely provided up to June 2004 (was stopped to encourage exclusive breastfeeding)</p> <p><b>Other:</b> Pilot Ministry of Health PMTCT programme (with support from MSF). The study retrospectively collected data from hospital records.</p>	July 2000-July 2005	Good
Anoje et al 2012 <sup>74</sup>	Cross River and Akwa Ibom States, South-South Nigeria	<p><b>Setting:</b> Rural (46%) and Urban (54%)</p> <p><b>Study site/s:</b> Six health facilities in two Nigerian states in the South-South region.</p> <p><b>Stage at which ANC sought:</b> Not reported (reported standard is 14 weeks)</p> <p><b>ANC testing strategy:</b> Not reported</p> <p><b>Follow-up schedule:</b> The infants were tested for HIV at six weeks of age, using DNA PCR on dried blood spots. HIV negative infants were tested at least six weeks after cessation of breastfeeding</p> <p><b>PMTCT Regimen for Mother:</b> HAART for eligible women. Ineligible women received short course zidovudine from 28 weeks and single dose nevirapine.</p> <p><b>PMTCT regimen for infant:</b> Single dose nevirapine and zidovudine for six weeks</p> <p><b>Whether replacement feeding freely offered:</b> Not reported</p> <p><b>Other:</b> Data were collected retrospectively from medical records.</p>	November 2007 and July 2009	Fair

Author & Year	City & Country	Description of programme	Programme years	Study quality
Black et al 2008 <sup>68</sup>	Johannesburg, South Africa	<p><b>Setting:</b> Urban</p> <p><b>Study site/s:</b> An integrated ANC ARV clinic at Johannesburg Hospital, a teaching hospital that offers ANC and HAART services</p> <p><b>Stage at which ANC sought:</b> Mean gestational age at initiation of HAART was 27 weeks; HAART was normally initiated a week after first ANC visit</p> <p><b>ANC testing strategy:</b> VCT (Opt-in)</p> <p><b>Follow-up schedule:</b> Babies were tested for HIV using DNA PCR at six weeks.</p> <p><b>PMTCT Regimen for Mother:</b> Eligible women are given HAART and referred to ANC ART clinic</p> <p><b>PMTCT regimen for infant:</b> Not reported</p> <p><b>Whether replacement feeding freely offered:</b> Not reported</p> <p><b>Other:</b> The ANC ARV programme at this hospital is integrated with ANC in order to prevent delays of HAART initiation to women thus prevent transmission. A retrospective analysis of hospital records.</p>	August 2004 –February 2007	Good

Author & Year	City & Country	Description of programme	Programme years	Study quality
Ciampa et al 2011 <sup>76</sup>	Zambezia Province, Mozambique (rural)	<p><b>Setting:</b> Rural</p> <p><b>Study site/s:</b> Alto Molócuè and Namacurra District hospitals</p> <p><b>Stage at which ANC sought:</b> Not reported</p> <p><b>ANC testing strategy:</b> Opt-out</p> <p><b>Follow-up schedule:</b> HIV testing by DBS PCR at age one month</p> <p><b>PMTCT Regimen for Mother:</b> HAART for those eligible; if not eligible twice daily zidovudine from 28 weeks and zidovudine/lamivudine/nevirapine during labour and twice daily zidovudine/lamivudine for one week after delivery</p> <p><b>PMTCT regimen for infant:</b> If mother was on HAART, single dose nevirapine; if on zidovudine short course then twice daily zidovudine for four weeks</p> <p><b>Whether replacement feeding freely offered:</b> No</p> <p><b>Other:</b> Retrospective analysis of hospital patient data. The paper reports on the outcome of an intervention that was undertaken to improve uptake of EID by direct accompaniment of mothers from the maternity clinic to the EID centre. However for this systematic review focus will be on the non-exposed group of the cohort i.e. the one that got standard care.</p>	September 2009-June 2010	<p>Fair</p> <p>Possibility of misclassification on bias as there was no tracking of babies; some who died could have been classified as LTFU</p>
Cook 2011 <sup>77</sup>	Zambézia Province, Mozambique	<p><b>Setting:</b> Rural</p> <p><b>Study site/s:</b> Alto Molócuè district hospital</p> <p><b>Stage at which ANC sought:</b> Not reported</p> <p><b>ANC testing strategy:</b> Opt-out</p> <p><b>Follow-up schedule:</b> Infants referred to “child at risk” clinics. EID using PCR test</p> <p><b>PMTCT Regimen for Mother:</b> HAART or short course zidovudine and single dose nevirapine</p> <p><b>PMTCT regimen for infant:</b> Zidovudine and single dose nevirapine</p> <p><b>Whether replacement feeding freely offered:</b> No</p> <p><b>Other:</b> This was an evaluation of the EID program within one year of inception. Retrospective hospital record review for patients who were seen in the PMTCT program.</p>	January 2007 to November 2008	<p>Fair</p> <p>Possibility of misclassification as mortality might have been classified as loss to follow up</p>

Author & Year	City & Country	Description of programme	Programme years	Study quality
Ferguson et al 2011 <sup>92</sup>	Ireland	<b>Setting:</b> 10-year observational cohort in Ireland <b>Study site/s:</b> PMTCT programme in Ireland <b>Stage at which ANC sought:</b> Not given <b>ANC testing strategy:</b> Opt out <b>Follow-up schedule:</b> All HIV exposed infants are referred to one clinic, Rainbow Clinic for management and follow-up <b>PMTCT Regimen for Mother:</b> ART for those eligible; if not eligible triple therapy ARVs for prophylaxis <b>PMTCT regimen for infant:</b> Changing with contemporary practise in the course of the study. <b>Whether replacement feeding freely given:</b> Not reported	January 1999-December 2008	Good
Goswami et al 2011 <sup>88</sup>	Kolkata, India	<b>Setting:</b> Urban <b>Study site/s:</b> OBGYN Medical College, Kolkata <b>Stage at which ANC sought:</b> Not reported <b>ANC testing strategy:</b> Opt-in. <b>Follow-up schedule:</b> Babies were followed up at the paediatric clinic of the hospital, and were tested using ELISA at age 18 months <b>PMTCT Regimen for Mother:</b> Single dose nevirapine <b>PMTCT regimen for infant:</b> Single dose nevirapine <b>Whether replacement feeding freely given:</b> No <b>Other:</b> Method of data collection not given.	January 2004-December 2007	Good



Author & Year	City & Country	Description of programme	Programme years	Study quality
Manzi et al 2005 <sup>78</sup>	Thyolo District, Malawi	<p><b>Setting:</b> Rural</p> <p><b>Study site/s:</b> Thyolo district hospital</p> <p><b>Stage at which ANC sought:</b> Not reported</p> <p><b>ANC testing strategy:</b> Opt-out</p> <p><b>Follow-up schedule:</b> Infants followed according to EPI schedule at 6, 10 and 14 weeks, and 6, 12 and 18 months. CTX-p was started for the baby at six weeks.</p> <p>HIV testing at 18 months</p> <p><b>PMTCT Regimen for Mother:</b> Single dose nevirapine (dispensed at 36 weeks of pregnancy)</p> <p><b>PMTCT regimen for infant:</b> Single dose nevirapine</p> <p><b>Whether replacement feeding freely given:</b> Provided for free for 12 months</p> <p><b>Other:</b> The hospital provided centralised PMTCT activities for the whole district (peripheral clinics/health care centres did not provide PMTCTC activities at the time of the study). Retrospective record review of hospital records.</p>	March 2002-September 2003	Good
Mirkuzie et al 2011 <sup>82</sup>	Addis Ababa, Ethiopia	<p><b>Setting:</b> Urban</p> <p><b>Study site/s:</b> 12 public health centres and three private hospitals in Addis Ababa with representation of the 10 sub-cities in Addis Ababa</p> <p><b>Stage at which ANC sought:</b> 65% were enrolled before 28 weeks of gestation</p> <p><b>ANC testing strategy:</b> Not reported</p> <p><b>Follow-up schedule:</b> Infant followed at six days (routine post-partum follow-up). HIV testing by DBS PCR at six weeks. Cotrimoxazole prophylaxis for breastfeeding infants at six weeks. Monthly follow up until six months, then every three months until 18 months.</p> <p><b>PMTCT Regimen for Mother:</b> HAART for those eligible; twice daily zidovudine from 28 weeks for those who are not eligible. Zidovudine/lamivudine/nevirapine intra-partum; zidovudine/lamivudine one week after delivery</p> <p><b>PMTCT regimen for infant:</b> Zidovudine for 1 week or one month depending on how long mother has been on medication</p> <p><b>Whether replacement feeding freely given:</b> Not reported</p> <p><b>Other:</b> Facility-based prospective cohort</p>	January 2009-December 2009	Good

Author & Year	City & Country	Description of programme	Programme years	Study quality
Namukwaya et al 2011 <sup>81</sup>	Kampala, Uganda	<p><b>Setting:</b> Urban</p> <p><b>Study site/s:</b> Mulago Hospital, Kampala</p> <p><b>Stage at which ANC sought:</b> Median gestational age 28 weeks (IQR 24-32)</p> <p><b>ANC testing strategy:</b> Not reported</p> <p><b>Follow-up schedule:</b> Infant testing using PCR at six weeks.</p> <p><b>PMTCT Regimen for Mother:</b> HAART for those eligible; if ineligible zidovudine twice daily from 28 weeks, single dose nevirapine and zidovudine/lamivudine tail after delivery <b>or</b> twice daily zidovudine/lamivudine from 33 weeks, single dose nevirapine and zidovudine/lamivudine tail after delivery</p> <p><b>PMTCT regimen for infant:</b> Single dose nevirapine and one week zidovudine</p> <p><b>Whether replacement feeding freely given:</b></p> <p><b>Other:</b> Strategies to encourage completion of visits were use of “peer” mothers, telephone reminders (50% of women had telephone contacts), home visits for women on HAART, treatment supporters for reminder of medication and clinic visits, and psychosocial support meetings by counsellors and “peer” mothers.</p> <p>Retrospective review</p>	January 2007 to May 2009	Good

Author & Year	City & Country	Description of programme	Programme years	Study quality
Nuwagaba et al 2010 <sup>87</sup>	Lake region, Tanzania	<p><b>Setting:</b> Not clear whether the region is urban or rural or both</p> <p><b>Study site/s:</b> Two regional hospitals, one zonal hospital and one health centre</p> <p><b>Stage at which ANC sought:</b> Not reported</p> <p><b>ANC testing strategy:</b> Not reported</p> <p><b>Follow-up schedule:</b> HIV testing by DNA PCR by DBS. Carers were given appointment cards to collect results after one month. Infants who were HIV positive who did not collect their results within 28 days were actively followed by phone and home visits.</p> <p><b>PMTCT Regimen for Mother:</b> Single dose nevirapine (53% did not receive it)</p> <p><b>PMTCT regimen for infant:</b> Single dose nevirapine (35% of infants did not receive it)</p> <p><b>Whether replacement feeding freely given:</b> Not reported; unlikely</p> <p><b>Other:</b> The paper was mainly aimed at reporting on the EID aspect, and not much was reported on the ANC packages. This was a pilot EID programme</p>	October 2006 to June 2007	Fair
Oladokun et al 2010 <sup>75</sup>	Ibadan, Nigeria	<p><b>Study site/s:</b> Urban</p> <p><b>Stage at which ANC sought:</b> University College Hospital Ibadan and its satellite clinics</p> <p><b>ANC testing strategy:</b> Initially opt-in, then opt-out from 2005</p> <p><b>Follow-up schedule:</b> Infants were tested at 18 months, using ELISA. DNA PCR since 2006.</p> <p><b>PMTCT Regimen for Mother:</b> Single dose nevirapine until 4<sup>th</sup> year when more complicated regimens were introduced</p> <p><b>PMTCT regimen for infant:</b> Single dose nevirapine</p> <p><b>Whether replacement feeding freely given:</b> Freely provided from second year of programme</p> <p><b>Other:</b> The hospital was one of the pilot PMTCT sites in Nigeria. For infant testing results only infants enrolled by December 2005 were included, to allow for testing by 18 months using ELISA (so the outcome used in this analysis is not affected by changes in PMTCT regimen and introduction of PCR testing). Retrospective review of hospital records.</p>	July 2002 to June 2007	Good

Author & Year	City & Country	Description of programme	Programme years	Study quality
Panditrao et al 2011 <sup>89</sup>	Maharashtra, India	<b>Setting:</b> Urban and rural <b>Study site/s:</b> 43 private sector hospitals in Maharashtra state, India <b>Stage at which ANC sought:</b> 76% registered after 20 weeks gestation <b>ANC testing strategy:</b> Not reported <b>Follow-up schedule:</b> Testing of infants using DNA PCR (stage of testing not given). Women are contacted by letter, phone calls or home visits when they miss their scheduled visit <b>PMTCT Regimen for Mother:</b> Zidovudine-based as per WHO guidelines <b>PMTCT regimen for infant:</b> WHO guidelines <b>Whether replacement feeding freely given:</b> Not reported <b>Other:</b> This was a private sector program. The study assesses risk factors for loss to follow up from the PMTCT program.	September 2002 to December 2008	Good
Sam et al 2003 <sup>91</sup>	London, United Kingdom	<b>Setting:</b> Urban <b>Study site/s:</b> King's College Hospital London <b>Stage at which ANC sought:</b> Not reported <b>ANC testing strategy:</b> Not reported <b>Follow-up schedule:</b> Infant follow-up visits, including HIV testing. Carers were contacted if there were missed appointments <b>PMTCT Regimen for Mother:</b> Not reported <b>PMTCT regimen for infant:</b> Not reported <b>Whether replacement feeding freely given:</b> Not reported <b>Other:</b> This study was published as a letter	1992 to April 2001	Good

Author & Year	City & Country	Description of programme	Programme years	Study quality
Seth et al 2012 <sup>90</sup>	New Delhi, India	<b>Setting:</b> Urban <b>Study site/s:</b> Kalawati Saran Children's Hospital <b>Stage at which ANC sought:</b> Not reported <b>ANC testing strategy:</b> Not reported <b>Follow-up schedule:</b> All HIV exposed infants are followed until they are 18 months old. Those who tested positive were started on HAART and followed further. <b>PMTCT Regimen for Mother:</b> Single dose nevirapine; 38% had no prophylaxis <b>PMTCT regimen for infant:</b> Single dose nevirapine; 61% got it <b>Whether replacement feeding freely given:</b> Not reported <b>Other:</b> This study is in a paediatric hospital, where HIV exposed infants have already been referred. No PMTCT activities are described. Retrospective review of hospital records	30 November 2006 to 31 December 2010	Fair
Shargie et al 2011 <sup>83</sup>	Addis Ababa, Ethiopia	<b>Setting:</b> Urban <b>Study site:</b> Zewuditu Memorial and Yekatit 12 Hospitals, in Addis Ababa <b>Stage at which ANC sought:</b> Not reported <b>ANC testing strategy:</b> Not reported <b>Follow-up schedule:</b> Testing of infants with DNA PCR at six weeks of age, and follow up for cotrimoxazole prophylaxis <b>PMTCT Regimen for Mother:</b> HAART for eligible women; zidovudine for ineligible with triple drugs intrapartum and two-drug tail for seven days <b>PMTCT regimen for infant:</b> Zidovudine for one week or one month depending on mother's duration of treatment <b>Whether replacement feeding freely given:</b> Not reported <b>Other:</b> Retrospective record review. The two hospitals serve patients with referral slips from all over the country	October 2008 to August 2009	Fair  Possible selection bias due to exclusion of records with missing data

Author & Year	City & Country	Description of programme	Programme years	Study quality
Sherman et al 2004 <sup>71</sup>	Johannesburg, South Africa	<b>Setting:</b> Urban <b>Study site/s:</b> Coronation Women and Children's Hospital <b>Stage at which ANC sought:</b> Not reported <b>ANC testing strategy:</b> Not reported; likely opt-in <b>Follow-up schedule:</b> Follow up of infants from six weeks to twelve months, with HIV testing using ELISA at 12 months <b>PMTCT Regimen for Mother:</b> Single dose nevirapine <b>PMTCT regimen for infant:</b> Single dose nevirapine <b>Whether replacement feeding freely given:</b> Freely given for first six months of life <b>Other:</b> Retrospective analysis of hospital records.	01 October 2001 to 31 October 2002	Good
Hassan et al 2012 <sup>73</sup>	Kilifi, Kenya	<b>Setting:</b> Rural <b>Study site/s:</b> Kilifi district hospital <b>Stage at which ANC sought:</b> Not reported <b>ANC testing strategy:</b> Opt-out <b>Follow-up schedule:</b> At the time, the standard was to follow all HIV exposed infants until 18 months with the following HIV testing schedule: PCR at 6 weeks, HIV rapid test at 12 months, and at 18 months if previously tested and continued breastfeeding <b>PMTCT Regimen for Mother:</b> Not reported <b>PMTCT regimen for infant:</b> Not reported <b>Whether replacement feeding freely given:</b> Not reported <b>Other:</b> The hospital followed all HIV exposed infants up to 18 months according to guidelines operating at that time, before guidelines to immediately treat any child testing HIV positive were in place.	August 2006 to August 2008	Good

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### 3.4.3 Study findings

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Table 3.3 shows the outcomes reported by each of the eligible studies. Twelve studies reported more than one outcome along the PMTCT cascade. It was possible to categorise the study outcomes of all studies according to timing of loss to follow-up along the continuum of care as follows: loss to follow-up of HIV positive mothers between ANC registration and delivery, loss to follow-up of infants by the age of three months, loss to follow-up of infants by 12-18 months of age and loss to follow-up of HIV positive infants before enrolment into ART programs. This classification enabled most outcomes reported in table 3.3 to be used in the synthesis of results.

**Table 3.3: Reported Outcomes**

<b>Author &amp; Year</b>	<b>Loss to Follow-up Outcome reported</b>	<b>Total at baseline</b>	<b>Number (%) lost</b>
Perez et al 2004 <sup>84</sup>	1) HIV positive women who did not collect results after testing during ANC	437	111 (25.4%)
	2) HIV positive women who did not deliver within health facility network (lost to follow up between ANC registration and delivery)	326	167 (51.2%)
	3) % Mother-infant pairs who were not among those attending at least two follow-up visits within the 18-month follow-up period	70	22 (31.4%)
Nlend et al 2012 <sup>85</sup>	Infants who did not come for testing at 6-8 weeks	587	103 (17.5%)
Moses et al 2008 <sup>79</sup>	Infants who did not come for testing at six weeks	3,160.	2,070 (65.5)
Lussiana et al 2012 <sup>86</sup>	1) HIV positive women not returning for subsequent ANC visits or delivery	382	164 (42.9)
	2) Infants lost to follow-up (not returning to hospital for evaluations after delivery).	218	42 (19.3)
Geddes et al 2011 <sup>70</sup>	Infants who did not return for testing at six weeks	699	128 (18.3)
Doherty et al 2005 <sup>69</sup>	Infants who did not return for testing at 12 months	1907	958 (50.2)
Azcoaga-Lorenzo et al 2011 <sup>72</sup>	1) HIV positive mothers lost to follow-up between ANC registration and delivery	1,668	632 (37.9)
	2) Infants lost to follow-up before determination of HIV status	767	148 (19.3)
Ahoua et al 2010 <sup>80</sup>	1) HIV positive mothers lost to follow-up before delivery (refused to enrol in PMTCT programme)	1. 1037	520 (50.1)
	2) Infants lost to follow up (defined as infants who had unknown HIV status at 18 months and who had missed their last scheduled appointment for at least two months before the beginning of the study)	2. 567	303 (53.4)
	3) HIV positive infants who remained lost to follow up after active follow-up	567	174 (30.7)

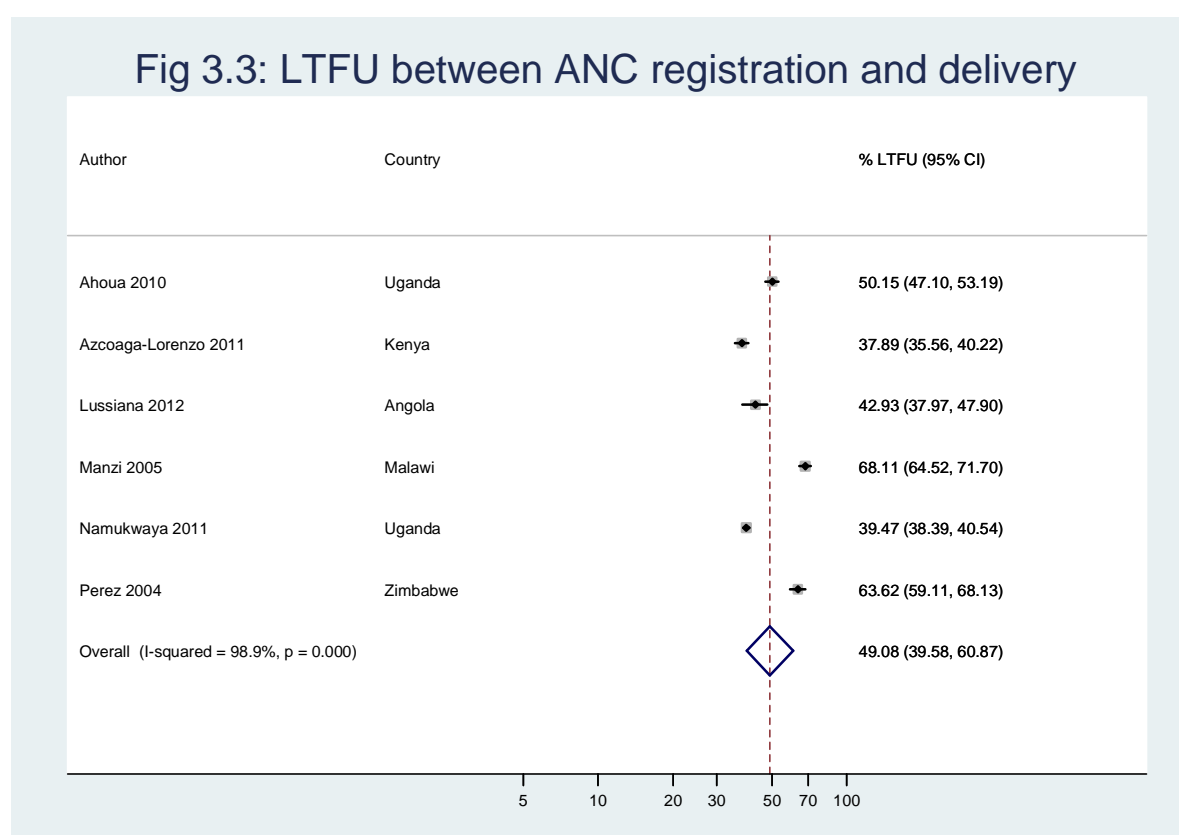


Author & Year	Loss to Follow-up Outcome reported	Total at baseline	Number (%) lost
Anoje et al 2012 <sup>74</sup>	HIV positive infants lost to follow up after PCR testing (infants were not enrolled into a paediatric ART programme)	125	85 (68)
Black et al 2008 <sup>68</sup>	Infants who did not come back for PCR testing at six weeks	493	191 (38.7)
Ciampa et al 2011 <sup>76</sup>	Infants who were not brought for HIV testing by age three months	332	247 (74.4)
Cook et al 2011 <sup>77</sup>	Infants who did not come back for early infant diagnosis	443	333 (75.2)
Ferguson et al 2011 <sup>92</sup>	1) Infants lost to follow-up before six weeks of age	964	17 (1.8)
	2) Infants lost to follow up before 3 months of age	964	40 (4.1)
Goswami et al <sup>88</sup>	1) Loss to follow up of pregnant HIV positive mothers between ANC registration and delivery	248	113 (45.6)
	2) Babies who did not return for testing at 18 months	95	36 (37.9)
Manzi et al 2005 <sup>78</sup>	1) Loss to follow up of mother at 36 weeks of pregnancy (did not come to collect single dose nevirapine)	646	358 (55.5)
	2) Loss to follow up of mothers by the time of delivery	646	440 (68.1)
	3) Loss to follow up of infant at six week post natal visit	206	10 (4.9%)
	4) Loss to follow up of infant at six month post natal visit	206	84 (40.8)
Mirkuzie et al 2011 <sup>82</sup>	Infants who did not return for HIV testing at six weeks	221	106 (48.0)
Namukwaya et al 2011 <sup>81</sup>	1) HIV positive women who were lost to follow-up between ANC registration and delivery	7,941	3,134 (39.5)
	2) Infants who did not come for HIV testing by age three months	4,807	2,442 (50.8)
Nuwagaba et al 2010 <sup>87</sup>	1) Infants whose HIV PCR results were not collected after testing (time point not given) includes both positive & negative	441	199 (45.1)
	2) HIV positive infants whose PCR results were not collected after testing (time point not given)	75	24 (32)
Oladokun et al	1) Infants who did not return to the hospital for testing at 18 months	303	63 (20.8)

Author & Year	Loss to Follow-up Outcome reported	Total at baseline	Number (%) lost
2010 <sup>75</sup>	2) Infants whose HIV results were not collected (includes both HIV positive and negative)	207	88 (42.5)
Panditrao et al 2011 <sup>89</sup>	1) Loss to follow up of HIV positive women between ANC registration and delivery	733	80 (10.9)
	2) Infants who were not brought for early infant diagnosis	770	151 (19.6)
Sam et al 2003 <sup>91</sup>	Loss to follow up of infants before final determination of HIV status	104	27 (26.0)
Seth et al 2012 <sup>90</sup>	Loss to follow up of infants at a paediatric hospital before determination of HIV infection	162	47 (29.0)
Shargie et al 2011 <sup>83</sup>	Loss to follow up of infants during follow up period after PCR testing at six weeks	118	36 (30.5)
Sherman et al 2004 <sup>71</sup>	Infants who did not turn up for testing with ELISA at 12 months	67	57 (85.1)
Hassan et al 2012 <sup>73</sup>	1) Infants lost before final determination of HIV status at 18 months	180	119 (66.1)
	2) Loss to follow up of HIV positive infants during follow-up	33	19 (57.6)
	3) Loss to follow-up of infants who were tested for HIV before collection of results (did not return to collect results)	102	46 (45.1)

### 3.4.3.1 Loss to follow-up of HIV positive pregnant women

Eight studies reported on loss to follow-up of HIV positive pregnant women between ANC registration and delivery. Two were from Uganda, two from India and one from each of the following countries: Kenya, Angola, Malawi and Zimbabwe. The percentage loss to follow up in these studies ranged from 10.9-68.1%, pooled estimate among the six Sub-Saharan African countries, 49.08% (39.6-60.9) PrI 22.0-100%,  $I^2$  value 98.9% (variation in study outcomes that is attributable to heterogeneity), (fig 3.3). The lowest proportion of 10.9% was reported in Maharashtra, India, a private sector PMTCT programme where women who had missed their appointments were followed up by letter, phone calls or home visits<sup>89</sup>.



*Fig 3.3 Loss to follow-up of HIV positive pregnant women between ANC registration and delivery*

*LTFU=Loss to follow-up*

On meta-regression analysis, only the type of PMTCT regimen (whether single dose nevirapine or more intensive regimens) was associated with LTFU; there was higher LTFU in the sites that offered single dose nevirapine than in those which offered more intensive regimens  $p=0.006$ . However this did not account for all heterogeneity; there was 92% residual heterogeneity.

Of note, the literature search and eligibility determination were set-up to find routine programs reporting on LTFU outcomes among HIV-exposed infants, and not pregnant HIV positive women. Therefore the outcome of LTFU among pregnant HIV positive women reported here does not reflect findings from those studies which did not report LTFU outcomes for infants.

### 3.4.3.2 Loss to follow-up of infants by age 3 months

Fourteen studies reported on loss to follow-up of infants soon after delivery; the infants typically did not return to the health care centre for HIV testing at six weeks. About half of the studies reported this as loss to follow-up at six weeks, but some studies allowed some time after the six weeks and reported loss by 8 weeks, or three months. In order to synthesise data from all the studies which reported on infants who did not come back for early infant diagnosis (EID) of HIV, a cut-off point of 3 months was reported i.e. synthesis of studies which reported LTFU by the age of three months. The percentage LTFU by age 3 months in the fourteen studies ranged from 4.1-to 75%. The pooled estimate from 11 Sub-Saharan African countries was 33.9% (27.6-41.5) PrI 15.4-74.2, fig 3.4.

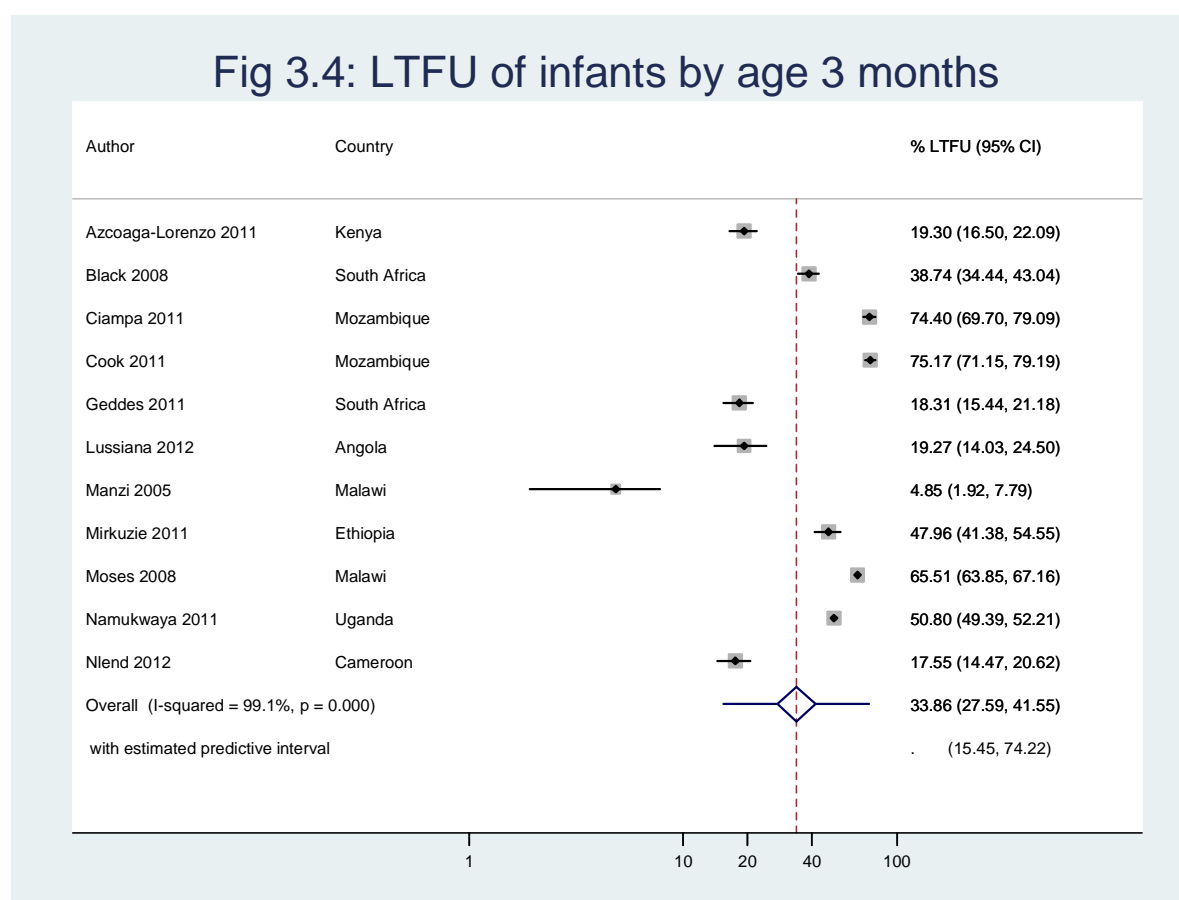


Fig 3.4: Loss to follow-up of infants by age 3 months

The lowest LTFU percentages were reported in Ireland and Malawi. In Ireland there was a system in place for follow-up of HIV-exposed infants which was enhanced by having a single centre for the coordination of the care of HIV-exposed infants. However, although the study in Malawi (Manzi et al)<sup>78</sup> reported low LTFU rates at six weeks, by the six-month postnatal visit 41% of infants had been lost; they were initiated on cotrimoxazole prophylaxis but were lost from further evaluation. In that study all PMTCT services were centrally provided at the hospital during the reported period. This is one example where centralisation of PMTCT services did not appear to reduce loss to follow up: authors reported that women may have increasingly found it more difficult to come back to the hospital because of long distances in an area where there was no public transport (women had to either walk or use bicycles) and would therefore have benefitted from decentralised services at local clinics. The programme in Cameroon<sup>85</sup> tracked clients using mobile phones; 90% of clients had mobile phones. This tracking may have improved their LTFU rates as they had comparatively lower LTFU rates than other sites of 17%. There was also good tracking of defaulters in the UK study in London<sup>91</sup>, which reported a loss to follow-up rate of 26%. Of note, the majority of infants lost to follow-up in that programme were born to African mothers, 89% compared to 71% of those who completed follow-up.

The two Mozambican studies both reported LTFU rates of about 75%, in a setting where there was lack of confidential counselling for women in crowded postnatal wards. The authors reported that this environment resulted in HIV positive women feeling uncomfortable about the possibility of disclosure thereby lessening their chances of returning to the hospital for the baby's early HIV testing. In addition, authors reported that the provision of EID services occurred in a different building from the one where referral was made possibly resulting in women getting lost between referral and follow-up. Related to this, in one of the studies in Ethiopia<sup>82</sup> some infants who had defaulted from EID had been to a health care centre for pentavalent vaccination at six weeks: 86% of infants were brought for pentavalent vaccine compared to 52% for EID at six weeks postpartum. This indicates that loss to follow-up from HIV-related care does not necessarily mean LTFU from the health care system, signifying the importance of integration of child health with EID services. These findings also point to the possibility that fear of stigma influenced the uptake of services.

None of the variables extracted from the studies explained the heterogeneity in the findings of LTFU by age three months.

### 3.4.3.3 Loss to follow-up of infants at 12 and at 18 months

Two studies (both from South Africa) reported on LTFU of infants after 12 months. The studies reported losses of 85.1% and 50.2% respectively. Both programs offered single dose nevirapine.

Five programs, three of which offered single dose nevirapine, reported on LTFU of infants by 18 months. Two were from India, with LTFU percentages of 37.9% and 29%, and one each from Uganda (53.4%), Kenya (66.1%) and Nigeria (20.8%).

### 3.4.3.4 Loss to follow-up of infants after HIV testing

Five studies reported on loss to follow-up infants after HIV testing (mostly during early infant diagnosis using PCR tests, and one used ELISA at 18 months): infants were lost during the recommended follow-up period after testing<sup>83</sup>, did not enrol into ART programs<sup>74</sup> or did not come back to collect HIV test results<sup>67,75,87</sup>. The percentage loss to follow-up of infants after testing ranged from 30.5-68.0%,  $I^2$  91.2% pooled estimate, 45.5 (35.9-57.6), PrI 18.7-100%, fig 3.5.

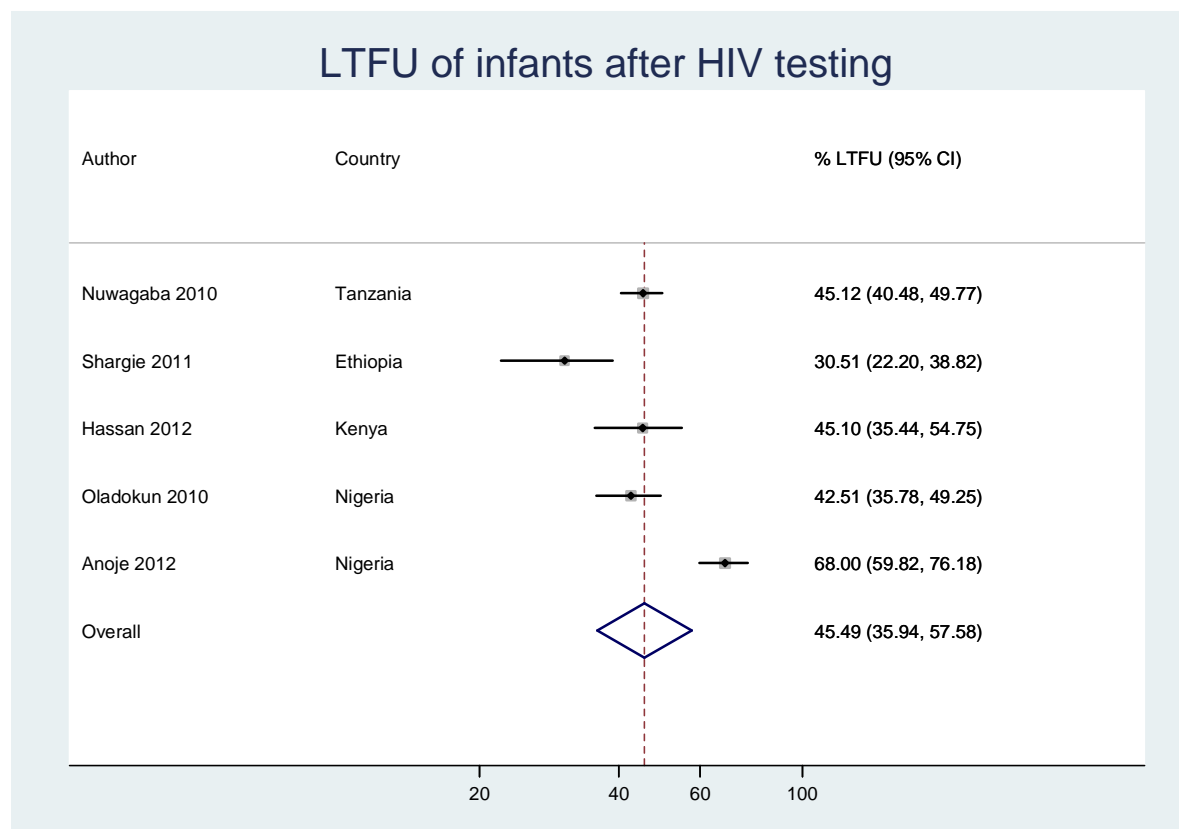


Fig 3.5: LTFU of infants after HIV testing

Again the benefit of active follow-up of defaulters was apparent in the study in Tanzania<sup>87</sup>, where the program actively tracked HIV positive infants who had not returned to collect results. As a result a lower percentage LTFU of 32% among HIV positive infants was observed compared to 48% among the HIV negative infants.

### 3.5 DISCUSSION

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This systematic review revealed that there is unacceptable loss to follow-up of HIV-exposed infants at various points of the care cascade. There was significant heterogeneity in the study findings; pooled estimates were reported together with predictive intervals to indicate the uncertainty in the estimates. An estimated 49% of HIV positive pregnant women are lost to follow-up between ANC registration and delivery (although this relates only to studies that reported on infant LTFU outcomes), while about 34% of infants do not return to the health care facilities for evaluations or early infant diagnosis. A further 45% of infants are lost to follow-up after HIV testing.

Of importance is that retention in a program is not necessarily equivalent to retention in the health care system; those women who have self-transferred out of a program to another facility should not be regarded as lost to follow-up. In this review, a third of programs either actively sought but did not find evidence of women self-transferring to other neighbouring health sites or provided the only PMTCT services in the communities in which they operated. Four studies<sup>68,76,77,91</sup> acknowledged the possibility of migration being misclassified as LTFU and the rest of the studies did not discuss this kind of LTFU.

If a woman is LTFU before delivery, she may not take her intrapartum ARV prophylaxis, and the baby will not be initiated on the necessary prophylaxis after delivery, and may not be registered for regular follow-up in the PMTCT programme. Current WHO guidelines which recommend that infants of unknown HIV exposure status who are seen at health care centres around the time of birth or at the first postnatal visit should have their HIV exposure status determined<sup>23</sup> are critical to reduce MTCT and need to be fully implemented by health care systems in order to re-enrol infants who have been lost from care before delivery.

Loss from care before delivery is not only unsafe for the baby, but for the mother as well. If the mother is lost to follow-up there may be delayed evaluation of her own disease progression and initiation of life-saving ART. Interventions are needed to retain pregnant

women in care. In this systematic review we found that programs which had an effective system for tracking defaulters had higher retention rates suggesting that programmers should consider incorporating interventions to actively track all women who have missed their appointments. It is important that tracking methods be appropriate for the setting. The programme in Uganda<sup>81</sup> had a high LTFU rate of 40% despite having a telephone tracking system, which may not have worked well because only 50% of clients had telephone contacts. On the other hand, telephone follow-up was appropriate in the programme in Cameroon where authors reported that more than 90% of women had phones<sup>85</sup>. Unfortunately tracking requires resources, and can be expensive depending on the setting. It is therefore important to have data on the relative costs and benefits of introducing such follow-up activities. In addition as tracking poses the risk of disclosure of HIV status, it is important that the tracking services are designed to ensure as much confidentiality as possible.

Of importance is the observation that even with active tracking there are still unacceptably high levels of loss to follow-up by the time of delivery, which means that there are likely other barriers that need to be overcome. Many qualitative interviews have been conducted to understand patient-level factors that influence HIV positive women's decisions to deliver in health care facilities.<sup>93-97</sup> Fear of involuntary disclosure of HIV status, fear of stigma, traditional beliefs, unfriendly health care workers, disbelief of HIV result, distance from health facility and cost of transport have been some of the barriers that have kept HIV positive women away from health care facilities. These patient-specific challenges have to be addressed so that programmes offer acceptable, culturally-sensitive services that will attract all intended beneficiaries.

Another programme characteristic that was found to be associated with loss to follow-up of HIV positive pregnant women was the type of ARV prophylaxis regimen that was provided; programs that offered single dose nevirapine had higher rates of LTFU than those which offered more intensive regimens. Single dose nevirapine was used in earlier programmes than dual/triple prophylaxis, when programmes were still learning how best to provide PMTCT services. An improvement as care shifts from single dose nevirapine to dual/triple therapy might indicate the progress made with time. In addition, dual and triple therapy necessitate more visits for prescription refills, exposing the woman to more counselling and support from health care workers which may increase knowledge and understanding of importance of PMTCT, acceptance of HIV status and the client's connectedness with the health care



system. Client-connectedness with the system has been found to be important in reducing missed clinic appointments<sup>98</sup>. The recent introduction of the WHO Option B+ programme, where all HIV positive pregnant or lactating women are given ARVs which are continued for life may help increase retention rates of women. Results from the Malawian Option B+ programme indicates encouraging retention rates of 77% 12 months after initiation of ART among women who did not transfer care during follow-up. Retention of mothers in care will likely reduce MTCT and likely also keep the HIV-exposed infants in care.<sup>99</sup>

By the age of three months, about 34% of infants delivered within the health system have been lost to follow-up. Again the importance of effective tracking of defaulters is apparent at this point of the care cascade. In the same way as for LTFU of pregnant women, other factors preventing attendance of infant testing visits are at play, meaning that active tracking of defaulters alone will not achieve optimum results. Qualitative studies<sup>97,100-102</sup> have reported barriers to early infant testing from the carer's perspective: the barriers are intrapersonal e.g. fear of positive result, believing that the child was healed through faith or traditional medicines, disbelief that PMTCT interventions work and intent to shorten the life of the child, time and money constraints and fear of disclosure of HIV status; interpersonal and community e.g. unsupportive male partners, stigmatising attitudes from family and community, cultural norms; health care system e.g. unfriendly health care workers, long queues and waiting times and different appointments for mothers and infants. Programmers in each context need to be aware of the barriers affecting their community and make appropriate culturally-specific interventions to enable a higher uptake of paediatric testing. Paediatric testing of HIV is a relatively new phenomenon that is being accepted at different rates in different communities. In a study in Western Kenya an acceptance rate of only 57% among children who had been offered testing was recorded<sup>103</sup>, yet a nationally representative survey in Zimbabwe reported positive attitudes towards paediatric testing; 92% reported that they would feel happier if their children were tested<sup>104</sup>. That cultural norms play a significant part may be further evidenced by the fact that the majority of infants who were lost to follow-up in the programme in London were born of African mothers; their reasons for dropping out of care may be similar to the barriers reported in African settings, where LTFU rates are highest. In addition, authors in the London programme reported that the mothers could have been facing immigration challenges, which may mean that as foreigners they might have felt less connected to London health services. There is evidence from a study conducted in Cote d'Ivoire that women who are more socioculturally and economically disadvantaged find it

more difficult to participate in PMTCT programmes<sup>105</sup>, the authors suggest implementation of structural interventions to promote retention, eg community mobilisation in affected communities, and economic and educational interventions.

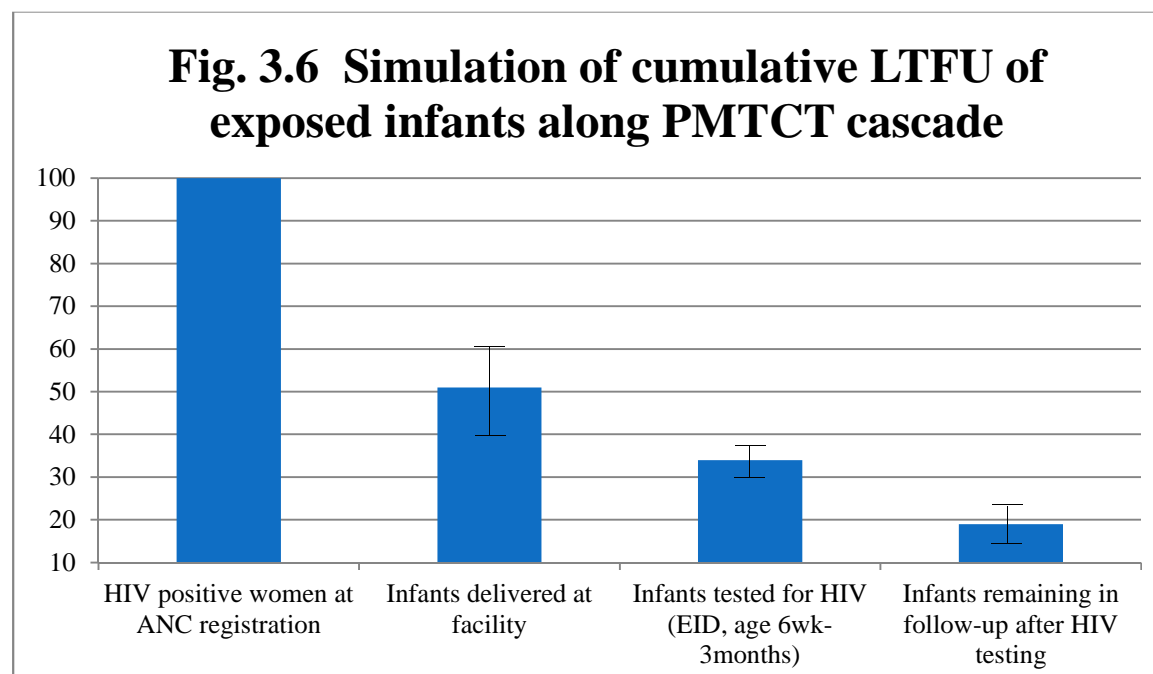
Another way to address LTFU of infants is integration of child health or EPI services with PMTCT programmes, as has already been recommended by WHO<sup>106</sup>. In one of the reviewed programmes in Ethiopia<sup>82</sup>, infants who had been lost to follow-up from the PMTCT programme at six weeks were documented to be attending the child health programme (i.e. had received pentavalent vaccine) at the same time that they were expected to have attended the EID facility. Integration of these two services may have reduced LTFU in the PMTCT programme. This necessitates proper documentation of HIV-exposure status on the child health card, a practise that has already been adopted in Lesotho, Zambia, Zimbabwe and several other countries<sup>1</sup>. Importantly, integration should ensure maintenance of confidentiality because fear of involuntary disclosure is a recurring theme in many qualitative studies exploring barriers to continued attendance of HIV-related care visits. The two programmes in Mozambique had very high levels of LTFU of 75%, which the authors partly attributed to lack of confidential counselling space.

Most programmes which reported on loss to follow-up at 12-18 months were older, and had mostly been giving single dose nevirapine. Higher levels of loss were reported at these points, indicating a progressive increase in LTFU with time. This also shows the value of continuous engagement with the health care system: appointments which are a very long time apart may promote greater loss to follow-up than regular appointments<sup>107</sup>. This may be less of an issue nowadays given the many effective interventions that necessitate regular follow-up of HIV-exposed infants for evaluations and prescription refills. The other potential reason for LTFU could be that mothers with thriving babies could have felt falsely reassured that the baby was HIV negative. Education of women on PMTCT is clearly important. Also it is possible that many of the babies had died.

The pooled LTFU of infants after HIV testing was 45.5%. All the programs reporting this outcome offered PCR (four studies) or ELISA tests (one study), where typically samples are sent to a central lab, and mothers are given appointments to collect results at a later date. Transport delays and other logistical challenges have been reported to increase result turnaround times<sup>52,108,109</sup>, and infants are lost during the waiting period. Fortunately, point-

of-care machines for EID are being tested and are likely to be on the market soon.<sup>110,111</sup> These will hopefully facilitate immediate decision-making and reduce LTFU. WHO recommend immediate initiation of ART in infants who test HIV positive<sup>23</sup>. There should be active tracking of infants whose results are positive in order to bring them into care. This was shown to be feasible and effective in the EID programme in Tanzania<sup>87</sup> which actively followed up HIV positive infants by phone and home visits if the HIV results had not been collected 28 days after the appointed date.

If we simulate a cumulative LTFU cascade using data obtained in this systematic review we will see that out of 100 HIV positive pregnant women who are enrolled into a PMTCT programme, only 19 infants are still in care after HIV testing, fig.3.6 below.



The strength of this systematic review is that it is a synthesis of real-life data from programmes which are actively implementing PMTCT services. It gives us a picture of how adept routine services are at implementing interventions that have already been proven to prolong the lives of children born to HIV infected mothers. Although studies were observational, they were generally of reasonable quality and did not suffer from significant bias in the measurement of LTFU outcomes.

There was significant heterogeneity in the study findings, with very wide predictive intervals. The main limitation of this review was our inability to fully explore the causes of the

heterogeneity in the study findings in meta-analyses. Accounting for the heterogeneity would have given us more information on the characteristics of programmes that achieve lower rates of LTFU. Although we were able to explain the bulk of the heterogeneity for programmes reporting LTFU of pregnant mothers before delivery, we were not able to do so for programmes reporting LTFU by age three months, and for those reporting LTFU at 12-18 months and after HIV testing. Nevertheless it was clear that programmes that have effective methods of tracking defaulters had better rates of follow-up.

Another limitation of the review is that it did not include grey literature, which is likely to have had some reports from routine programs. This is a trade-off that was made by preferring peer-reviewed publications which were viewed to have been more vigorously reviewed.

Another limitation is related to the use of one researcher in the review. As per standard in systematic reviews, 5-10% of abstracts should be checked by another researcher for inter-rater reliability. However this was not done because of logistical and financial challenges. Although due care was exercised during determination of eligibility of papers, and in using standard procedures and forms for quality review and data extraction, a quality check on 5-10% of abstracts would have been helpful.

In conclusion, there are unacceptably high levels of loss to follow-up of HIV-exposed infants at important points of the PMTCT cascade. Effective tracking of defaulting clients reduces loss to follow-up rates. Programmers should consider initiating effective interventions for tracking defaulting clients. In addition, investigation of patient level and context specific factors that limit adherence to visit schedules could be used to develop culturally sensitive retention interventions.

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*This systematic review has been published as a journal article in AIDS journal; a copy of the paper is appended in Appendix 8.*

## **CHAPTER 4: METHODS**

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The study was conducted at Mbare Polyclinic, in Harare. Written approval to conduct the study was obtained from the Ministry of Health and Child Welfare (MoHCW) and City of Harare. Ethical approval was obtained from the following three committees: University of Zimbabwe College of Health Sciences Ethics Committee, the National Ethics Committee (Medical Research Council of Zimbabwe), and the UCL Ethics Committee.

### **4.1 STUDY DESIGN**

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The study was divided into two phases. Phase 1 was aimed at understanding the policy and guidelines for implementation of cotrimoxazole prophylaxis among HIV exposed infants in Zimbabwe. In addition to studying the policy and guidance documents, this involved conducting key informant interviews with individuals holding key positions in the implementation of PMTCT services at MoHCW and City of Harare.

Phase 2, which was a study of implementation activities for cotrimoxazole prophylaxis at Mbare Clinic, was aimed at understanding the implementation challenges in the various stages of the cotrimoxazole care cascade. This involved conducting a cross-sectional survey among women who had just delivered at the clinic to evaluate the care given during the antenatal care period, with particular reference to whether there had been identification of HIV exposure status for the infant i.e. whether the mother had been tested for HIV. In addition, HIV positive women were followed up at six weeks post-delivery to investigate whether their babies had been started on cotrimoxazole prophylaxis. Willing HIV positive women whose babies had been started on cotrimoxazole prophylaxis were followed up monthly until 6 months post-delivery to study their experiences with collecting prescription refills and keeping the baby on cotrimoxazole prophylaxis. As part of this, qualitative in-depth interviews were conducted with the women at 4-5 months post-delivery to explore their experiences with keeping their babies on cotrimoxazole prophylaxis.

Preliminary analysis of Phase 2 data revealed that a critical impediment to the first part of the PMTCT cascade (identification of HIV exposure status) was that some women did not get tested for HIV because they had not sought antenatal care. Therefore qualitative in-depth interviews were conducted with women who had not registered for ANC, and those who had

registered late, to explore their reasons for this. Preliminary analysis also revealed that there was poor attendance of the six week postnatal visit, which is the visit when the baby should be started on cotrimoxazole prophylaxis. In-depth qualitative interviews were held with women who had failed to attend the six week visit to explore their reasons for this. In addition, clinic records for participants delivering at the clinic over a one-month period were surveyed to investigate whether attendance of the six-week postnatal visit differed according to HIV infection status.

This thesis focused to a large extent on the earlier part of the PMTCT cascade but did not look at later parts (e.g. evaluating the coverage of maternal and infant ART prophylaxis around delivery and uptake of infant HIV testing and ART uptake for HIV positive infants) because the later parts entailed larger sample sizes and longer follow-up in the study, which could not be done with the limited PhD fellowship funding.

## **4.2 METHODS FOR PHASE 1**

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Key informant interviews (in-depth interviews) were conducted with the following:

1. The national representative of MoHCW responsible for implementation of PMTCT services. This key informant was a 50-year old, Shona woman who is a paediatrician. She holds a very senior position in MoHCW where she is the national PMTCT services coordinator. As head of the PMTCT department her role is to ensure the proper implementation of PMTCT services in all public health institutions. She reports directly to the head of AIDS and TB services in the MoHCW. During the interview she was asked about the policy for cotrimoxazole prophylaxis and follow-up of HIV infected mothers, and about implementation procedures and challenges faced.
2. A representative of the City of Harare Clinic Management responsible for Reproductive Health Services. This was a 52-year old woman who held a senior position within the City of Harare, where her role was to provide oversight of the implementation of sexual and reproductive health services across all the clinics within the City of Harare Network. She is a nurse midwife, with decades of experience in the nursing field. She has spent most of her nursing career within the City of Harare, having been promoted through various management positions up to the position she held at the time of interview. In her position she worked very closely with the

MoHCW department responsible for sexual and reproductive health services. During the interview she was asked about the policy for cotrimoxazole prophylaxis and follow-up of HIV infected mothers, and about implementation procedures and challenges faced.

3. The Stores Manager at NatPharm, the national agency responsible for drug distribution. This was a 25-year old pharmacist with two years' experience in that position. She was responsible for managing the Stores: receipt of drugs and medical supplies from donors or wholesalers and distributing them to health care centres in the public health system. Although she had a management position and supervised a few staff she worked with, her position within NatPharm was not very senior. She was asked about the drug distribution process, challenges faced and the adequacy of human and material resources.

The key informant interviews were audio-recorded.

Selection of the key informants was not done by the candidate. In all three instances the candidate wrote a formal letter to the heads of the institutions asking for permission to have a discussion on the study topic with a relevant person from the organisation. Upon granting permission to the candidate, the head of institution would refer the candidate to the member of staff who (because of the work they were doing) was believed to be best suited to respond to the questions. None of the three key informants were known personally by the candidate.

In addition to the key informant interviews, MoHCW and City of Harare guidelines, M&E tools and standard operating procedures relevant to the implementation of cotrimoxazole prophylaxis to HIV exposed infants and care of HIV infected mothers were reviewed.

### **4.3 METHODS FOR PHASE 2**

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Phase 2 of the study was conducted at Mbare Clinic, a description of which follows.

#### **Background information on Mbare clinic**

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Mbare Clinic is a large polyclinic situated in one of the oldest suburbs in Harare, called Mbare. Mbare is home to the largest food and vegetable market in the country, a market for traditional artwork, and a second-hand clothing market. It is one of the poorest communities

in Harare, with high levels of unemployment and crime. Most employment is informal, being centred around the markets mentioned above.

Mbare Clinic is centrally-located in Mbare suburb. It is owned and financed by the City of Harare although it gets assistance in the form of supplies, equipment and clinic renovations from some humanitarian organisations e.g. ICRC, Zimbabwe Network for Health and ZimPro. About 100 metres from the clinic is the country's busiest long-distance bus terminus. The terminus is adjacent to Harare's busiest bus stop where local commuter buses from most high-density suburbs drop-off and pick up passengers. Although the clinic has a catchment of about 140,000, in reality it caters for a much larger population than this as it is frequently used by patients who come from other residential suburbs or cities. The Clinic is made up of three departments described below:

**Outpatients Department** - This is a busy clinic for curative services for adults and children. It sees about 4,000 patients a month. Chronic care patients, including those coming for HIV care (ART prescription refills and cotrimoxazole prophylaxis) are seen at this clinic. It is open every day of the week; from 8am to 4.30pm. Patients pay fees to access services as described above. The outpatients department is staffed by nurses, who refer complicated cases to Harare Central Hospital or to the attention of the district medical officer who visits Mbare clinic on Mondays, or to a volunteer doctor, who conducts weekly clinics on Tuesdays.

**Family Health Services (FHS) Clinic**-This is the clinic where babies and children are seen for immunizations and growth monitoring. All children under five years within the clinic's catchment area are expected to visit the clinic on a monthly basis, starting with an initial visit at about 10 days after birth. No charges are levied for services provided. However, should a child fall sick and there is no proof that they regularly attend the child health clinic, they will be asked to pay a consultation fee of US\$3 when they seek treatment at the Outpatients Department. The FHS clinic also provides family planning services. In addition, it has a community department which conducts home and community visits to ensure the general upkeep of community health standards (eg through inspecting day care centres and schools for compliance with set hygiene standards) or to attend to individuals who need medical help but are unable to visit the clinic.



**Maternity Clinic (also called Edith Opperman Maternity Clinic)**-This is the department responsible for providing antenatal care (ANC), delivery and post-natal services (to 6 weeks post natally). About 400 babies per month are delivered at the clinic.

**Pictures of Mbare Clinic**



**Picture of the Outpatients  
Department**




**Picture of the ANC clinic (yellow)  
and part of the FHS Clinic**



**Picture of the Edith Opperman  
Maternity Clinic**

Phase 2 of the study was made up of different studies which employed different study designs. Figure 4.1 shows a schematic overview of all the phase 2 studies.

**Fig 4.1: Summary of Phase 2 Studies**


D o m a i n	Investigating facility capacity to implement CTX-p	Investigating challenges with identification of HIV exposure status	Investigating barriers to initiation of CTX-p to babies at six weeks	Exploring mother's experiences with adherence to CTX-p
	Nurse Interviews	Cross-sectional survey among postnatal women	Survey of six-week visit clinic records	Follow-up study of mother-baby pairs
S t u d i e s	CTX Stock assessments	Qualitative study to explore barriers to ANC	Participant interviews at six-week visit	Qualitative study to explore adherence issues
			Qualitative Interviews to explore barriers to six-week visit attendance	

Qualitative studies are indicated by green boxes.

#### 4.3.1 Assessment of implementation activities at Mbare Polyclinic

##### Staff Interviews

Two nurses at Mbare Clinic were interviewed to determine what systems were in place for identifying HIV positive women, enrolling them into the PMTCT programme and ensuring that HIV exposed infants were offered cotrimoxazole prophylaxis. The nurses were also asked to assess the efficiency of the system and barriers to implementation of cotrimoxazole prophylaxis including any challenges with drug supply. The interviews were audio-recorded.

One of the nurses was a middle-aged (age not asked) Sister-in-charge (a midwife) responsible for oversight of the outpatients clinic. Although at the time of interview she was in charge of the outpatients clinic, she had experience of being in charge of the other two clinics, the family health services clinic and the maternity clinic. The sisters-in-charge at Mbare Clinic frequently rotate positions among the three clinics.

The other nurse who was interviewed was a nurse midwife (in her thirties) who did not have a management role at the clinic. At Mbare Clinic, nurses frequently rotate positions and can work in any of the three clinics. At the time of interview she was working at the maternity clinic where she was providing care to labouring and postnatal women.

As for the other key informants described in section 4.2, the candidate did not select the key informants: they were recommended by the clinic manager. None of the key informants were known personally to the candidate.

#### Assessment of stock levels

At three time points (unannounced to clinic staff) during the course of Phase 2 of the study, stock levels of cotrimoxazole were audited. Expiry dates were noted and conditions (e.g. temperature and security) under which these supplies were kept were examined. The means of accounting for stock was also assessed.

#### Patient survey

Between 21 September 2010 and 10 February 2011, a cross-sectional survey was conducted among women who had just delivered babies at the clinic. Women who met all the following criteria were asked to participate in the survey:

- Women who had delivered on or after 21 September 2010, as long as they were not yet due for the six weeks postnatal visit
- Women who resided in Mbare at the time of recruitment (as determined by the address on the participant's medical record). This was necessary because women who did not reside in Mbare were not expected to come back to Mbare Clinic for postnatal visits but to go to the clinics in their respective places of residence
- Women who were willing and able to give written informed consent for participation. (There were procedures for consenting illiterate participants in the presence of a literate witness of their choice).

Participants were recruited from the maternity clinic post-natal ward and the well-baby clinics (mainly at the 10 day post natal visit). Recruitment was conducted during daytime hours (8am to 430pm) during weekdays; no recruitment was done on weekends. All women who attended the two clinics above and met the inclusion criteria were asked to participate in the study.

It should be noted that recruiting from the clinic was not ideal because only the views of clinic attendees were captured, and no data was captured on women who did not deliver at the clinic or those who chose not to attend the 10-day postnatal visit. Data from this study is therefore only applicable to attendees of Mbare Clinic, and cannot be applied to the general

population in Mbare since it is highly likely that the views and challenges faced by non-attenders differ from those of attenders. With the limited PhD fellowship funding, it was not possible to employ extensive techniques to recruit women who delivered at home (they would be more difficult to find and so the study would be more costly).

Participants who had given written informed consent were asked to complete an interviewer-administered questionnaire where they were asked about their experience of antenatal care (ANC), specifically the location and timing of their ANC visit(s), whether they underwent HIV testing, received their HIV result and if positive whether they disclosed their HIV status, received and took ARVs for PMTCT. In addition women were asked about their past obstetric history including pregnancy loss and vital status of previous children, their general health and previous HIV testing behaviour (see Appendix 1 for the questionnaire). The questionnaire was translated into Shona, the local language in Zimbabwe. In Zimbabwe medical records are kept on a patient-held medical record card. Where possible, participant responses were cross-checked with the medical record card, e.g. for date of ANC registration and HIV results. Participants held this medical record and were asked to show it to study staff with the understanding that they could refuse if they did not want study staff to have a look at their record.

The cross-sectional survey interviews were conducted by a trained nurse-interviewer. There were standard operating procedures for identification and recruitment of participants and for completing the questionnaires. The nurse was trained in these procedures and was supervised to ensure that she adhered to them.

Women were asked if they intended to return to the clinic for their 6-weeks post-natal visit. HIV positive women who said they were planning to return were asked if they could be re-interviewed at that time. Written informed consent was obtained for participation at the six-week visit and for home follow-up in the event that they failed to attend. Their locator details were collected.

#### Participant interviews at six-week post natal visit

The following participants were eligible for interviewing at the six-week visit:

- HIV positive

- Having participated in the baseline patient survey
- Having had a live birth
- Women intending to return to the clinic for the six-week visit
- Women who had given written informed consent to participate at the six-week visit

As HIV positive participants completed their 6 weeks post-natal visit they were interviewed to collect information on their own health and the baby's health using a semi-structured questionnaire (Appendix 2). The mother's medical records were reviewed to see if HIV positive women had been examined to determine their WHO clinical disease stage and if they had been referred for further HIV care (e.g. clinical staging, CD4 testing, ART). The baby's medical record cards were examined to see if they had been prescribed cotrimoxazole prophylaxis and if so if it had been dispensed. When this did not happen reasons for this were explored. Women and babies who had not received appropriate referral/care were referred back to clinic staff. Women who did not attend their 6 weeks post-natal visits were contacted at home and their reasons for non-attendance were explored in qualitative in-depth interviews.

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#### **4.3.2 Assessment of adherence to cotrimoxazole prophylaxis**

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HIV positive women (including some who did not participate in the study at the six-week visit) who were prescribed cotrimoxazole prophylaxis for their baby at their six weeks post-natal visit were invited to take part in the adherence sub-study. Separate written consent was obtained. Women who agreed to take part were seen by the study nurse at the following clinic visits over the following 6 months: 3, 4, 5, and 6 months. They were asked to bring their cotrimoxazole container for assessment of remaining amounts at each of the visits.

Adherence study participants were also asked to provide permission to be visited at home by the nurse interviewer for home assessment of adherence. Adherence was estimated using the following parameters:

- comparison of observed with expected remaining amounts of medicine at each clinic visit and at unscheduled home visits
- completion and timing of prescription refill visits at the clinic
- direct observation of mother dispensing cotrimoxazole to her baby in home environment
- self-reports

In addition to assessing adherence directly, women taking part in the adherence sub-study were interviewed in-depth at 4-5 months post-delivery to assess their understanding of their HIV status and what it meant for them and their baby in terms of follow-up, their understanding of the rationale for cotrimoxazole prophylaxis and its administration and the importance of adhering to it. Women were asked whether their partner was supportive of cotrimoxazole prophylaxis for their child. The in-depth interviews were held in private in one of the clinic rooms at Mbare Clinic.

All survey tools and data collection forms used in Phase 2 of the study were piloted before use.

Participants in all the studies were offered an incentive of \$5 for study participation. This is the amount that the Zimbabwean national ethics committee (Medical Research Council of Zimbabwe) recommends as not coercive for study participation.

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#### **4.3.3 Preliminary analyses of survey data**

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Preliminary analysis of survey data were conducted after 199 women had been enrolled (December 2010).

##### Purpose and methods

The purpose of the preliminary analysis was to evaluate data collected up to December 2010 for its adequacy and thus inform future data collection procedures. Data analysis proceeded as described in section 4.5, data analysis.

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#### **4.3.4 Incorporation of findings of preliminary analysis into study design**

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The main findings of the preliminary analysis were:

1. 23% of participants did not register for antenatal care (ANC). Of those who registered, the mean number of weeks gestation at registration (time to ANC registration) was 28.9 (95% CI 27.7-30.1), which was much later than the 16 weeks recommended by Ministry of Health and Child Welfare (MoHCW) at that time.
2. Some HIV positive participants who had not registered for ANC but had been tested for HIV at other testing centres chose not to disclose their HIV status to the health care workers at delivery. As a result, at the time of delivery they (and their infants)



did not receive appropriate care for HIV positive women or HIV exposed infants. This applied to three participants.

3. Of 19 HIV positive women who were due for attendance of 6-weeks post-natal visits, only 6 attended.

Based on these findings, the following changes were made to the study procedures:

#### 4.3.4.1 In-depth interviews

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In-depth interviews were conducted with the following participants:

1. **Participants who did not register for ANC** to explore why they did not register. HIV positive participants were also asked about the possible reasons why some women who have been tested in other testing centres choose not to disclose their HIV status to the nurses.
2. **Participants who registered later than 24 weeks gestation** to explore why they delayed registering.
3. **Participants who did not attend the six-week post-natal visit** to explore the reasons for non-attendance.

Ethical approval for these changes was obtained after the baseline patient survey was complete, so additional participants were recruited for the qualitative study on barriers to ANC registration.

The in-depth interviews were held in private in one of the clinic rooms at Mbare Clinic. Interviews took between 30-minutes to one hour, with an average length of 45 minutes.

When the study was initially designed, there were plans to do the patient survey and longitudinal follow-up of HIV positive women at two sites, one urban and one rural. The fellowship funding for the study could not extend to both expanding the study within the urban site at Mbare Clinic and going to a rural site as originally proposed. Given the importance of exploring the barriers to cotrimoxazole prophylaxis in full, the candidate felt it would be better to collect more in-depth data from the urban site instead of collecting less in-depth data from both rural and urban sites. An additional financial constraint was that after the fellowship was funded HIV prevalence in Zimbabwe declined and, with the change of the economy following the adoption of the US dollar as currency, the cost of implementing the

study at the rural site increased making it logistically impossible to include a rural site using the very limited fellowship funding.

The methods for data collection and analysis of in-depth interviews are described in the section for qualitative data collection and analysis, section 4.6.2.

#### **4.3.4.2 Assessment of rates of non-attendance of six-week post-natal visit**

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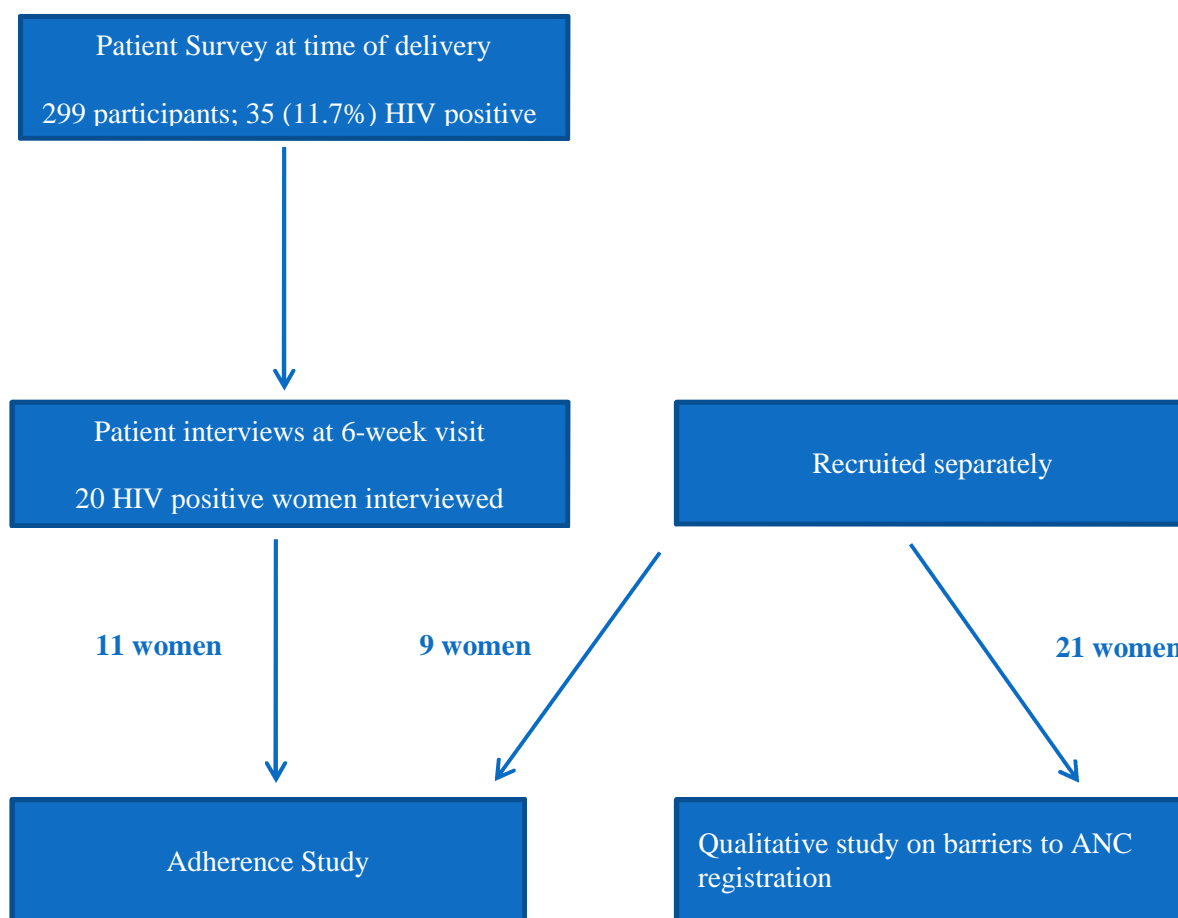
The six week post-natal visit is important for HIV positive women because it is when their babies are initiated on cotrimoxazole prophylaxis. Given the poor attendance rates of HIV positive women at the six week visit, I sought to determine whether this was a general trend for all women or whether it was limited to HIV positive women. It would be important to investigate the reasons if it emerged that HIV positive women were more likely to miss their six week visit appointment than HIV negative women. An assessment of six-week visit attendance rates at the clinic was done using the methods described below.

##### Methods

Data on characteristics of women delivering at Edith Opperman Maternity Clinic (the Maternity Clinic at Mbare Clinic) over a four-week period from 15 November to 12 December 2010 were extracted from the delivery register kept by nurses at the clinic using a standard questionnaire (Appendix 3). The following characteristics were recorded: name, age of participant, date of delivery, whether the woman had registered for antenatal care, HIV status and area of residence. The number of characteristics collected was limited by the data recorded in the delivery register. In addition, the six week clinic attendance register was used to check whether the woman had attended the six week visit. To ensure that we did not miss any six week visit attendance, for each woman we searched entries made at 5, 6, 7 and 8 weeks after her delivery. As the women often use their married and maiden names interchangeably, both names were extracted from the delivery register and both were used when searching the six week register. In cases where there wasn't an exact match between our questionnaire and the name in the six weeks register, identity was verified using the home address and date of delivery of the baby.

Data extraction was done by the study nurse.

Fig 4.2 below is a flow chart which indicates which women participated in each of the studies (does not include in the clinic record review).



*Fig 4.2: Flow chart of women participants in the various studies*

#### 4.3.4.4 Details of the study team (data collection team)

All key informant and in-depth interviews were conducted by the candidate. The candidate is a black Zimbabwean woman who is fluent in Shona and Ndebele, the two main local languages in Zimbabwe. At the time of data collection in 2011, the candidate was 32 years old and was employed as a research fellow in the research organisation where the research was done.

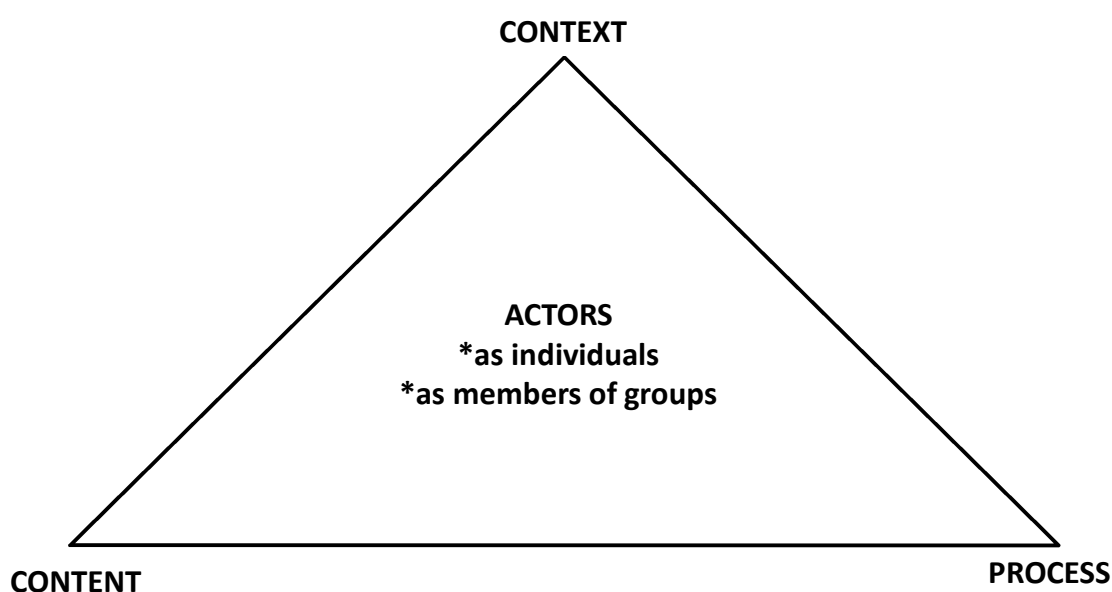
Patient survey data were collected by the study nurse, who was 27 years old in 2011. The study nurse was a black Zimbabwean woman who was fluent in Shona, the main local language in Harare.

#### 4.4 DATA ANALYSIS METHODS FOR PHASE 1 OF THE STUDY

Key informant interviews were transcribed and analysed thematically. A description of the content of the policy and guidance documents was made. A retrospective policy analysis was

performed using data obtained from both the key informant interviews and document review. The analysis was done using a health policy framework called the policy triangle framework<sup>112,113</sup> as an analytical framework. This framework has four components to it, namely context, content, process and actors. Using data from the key informant interviews and document review as appropriate for each component, a description of the policy under each of the four components was undertaken. This ensured that the policy analysis did not only focus on content of the policy, but also on actors, context and process, as is good practise in policy research (see fig 4.3 below).

**Fig 4.3: A model for health policy analysis<sup>112</sup>**



## 4.5 DATA ANALYSIS METHODS FOR QUANTITATIVE DATA

### 4.5.1 Data Quality Control and Cleaning

The nurse-counsellor who collected much of the clinic based data was trained on how to interview and on questionnaire completion, including how the skip patterns worked. The first 20 questionnaires completed were checked by the candidate for errors, and feedback on errors was given to the nurse counsellor.

Quantitative data were entered by a data assistant into a Microsoft Access database. As a quality control measure the data were double-entered, and the two data files were compared. Where there were discrepancies the source document was used for verification.

The data were then exported into Stata Version 9.0<sup>114</sup>, the statistical package that was used in the analysis.

The data were cleaned by running the following checks through each variable:

- Checking for missing values
- Checking for inconsistencies between related questions
- Verifying that values made sense or were within normal ranges (for example dates, participant ages, number of weeks gestation when ANC was first sought)

Where errors or missing values were noted, source documents were used to verify the data. Values which were clearly wrong and were interviewer errors (e.g. implausible year of birth for the participant) were marked as missing. Values which were suspicious but had been reported as such by participants, e.g. a very high monthly income figure, were left as they were.

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## **4.5.2 Analysis Methods for Patient Survey Data**

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The proportions of women in various categories of participant characteristics were calculated.

### **4.5.2.1 Determination of Factors Associated with ANC Registration**

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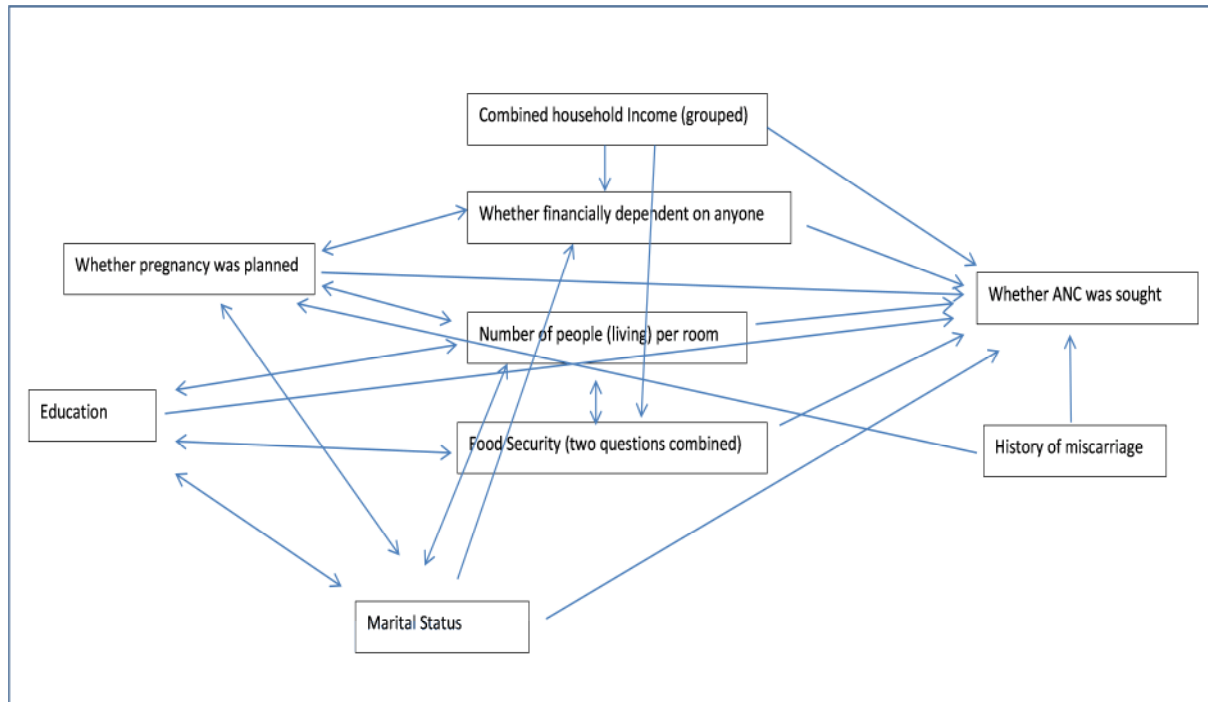
Chi-squared tests of association for each of the variables with ANC registration and with each other were computed. Using Maentel-Haenzel methods, the effect of each of the participant clinical, demographic and socio-economic characteristics on ANC registration was investigated. Classical methods were used first in order to get a sense of how the variables were associated with each other before going on to logistic regression. Univariable analysis was then conducted using logistic regression.

#### Multivariable analysis

Using information obtained from the investigation of chi-squared tests, and also general knowledge of how factors may relate to one another in real life, including possible interactions (effect modifications), a causal diagram was drawn (fig 4.4). The causal diagram was useful in providing a visual picture of how all the studied factors related to each other and to ANC registration. When thinking about which variables to include in the multivariable analysis model, consideration was made of the principle that variables which are on the

causal pathway should not be included in the model. The causal diagram was helpful in identifying which variables were on the causal pathway.

**Figure 4.4: Causal diagram used to make decisions on which factors to include in model for multivariable analysis**



Another guiding principle in the selection of variables for the model was that variables that are deemed to measure the same thing (collinear variables) should not both be included in the same model because this can result in an unstable model, or the computer might fail to fit the model. In light of this, decisions had to be made on which socio-economic variables to include in the adjusted logistic regression model to avoid collinearity. Available variables were:

1. Whether the participant earned an income
2. Monthly income earned by the participant (those who reported that they did not earn an income were assigned an income of zero)
3. Whether the partner earned an income (if the woman was married)
4. Monthly partner income (an income of zero was assigned for partners who did not earn an income)
5. Combined household income (which was obtained by adding the participant's income to the partner income for married women, and keeping the participant's monthly income as it was for unmarried women)

6. The food security variable. This variable was derived from the two food security questions in the questionnaire. One asked whether, in the past week, an adult in the participant's household had not eaten or eaten less in order to ensure that there was enough food for children. The other question asked whether, in the past week, the participant had spent the whole day without eating because there was no food in the house. The binary food security variable was created to have 1) participants who had no food security problems i.e. answered no to both questions; and 2) participants who answered yes to either of the food security questions.
7. Whether the woman was financially dependent on anyone
8. Number of people per room in the participant's household
9. Tenancy (whether the house is owned/rented/participant lived with relatives)
10. Type of toilet used
11. Source of water

For quantitative continuous variables, decisions had to be made on whether to fit the model with the variable as a continuous variable or as a grouped categorical variable. Care had to be taken in fitting models with continuous variables because such models assume a linear relationship between the explanatory variable and the dependant variable. In view of this checks for departure from linearity were done using likelihood ratio tests, comparing models with continuous variables and those with grouped categorical variables. Where it was clear that a linear relationship existed between the quantitative explanatory variable and the dependent variable, the model was fitted with the continuous variable so as not to lose data through grouping.

Investigations for effect modification were done between the following variables:

1. Education and marital status
2. Marital status and whether pregnancy was planned
3. Whether pregnancy was planned and history of miscarriage
4. Marital status and household income

Likelihood ratio tests were used to test for effect modification by comparing the models with interaction terms and those without.

An explanatory variable was eligible for inclusion in the final model if there was evidence of its association with ANC registration at the  $p < 0.1$  level. Having decided which variables were potentially suitable for inclusion in the final model, multivariable logistic regression was



conducted by adding to the model each of the potential variables in turn, and conducting a likelihood ratio test to check if the model was improved by the addition. Interaction terms were included where effect modification had been noted to be present.

#### **4.5.2.2 Determination of Factors Associated With Knowledge of HIV Status During Pregnancy**

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The proportion of women who knew their HIV status during pregnancy was computed by adding the number of women who were tested during pregnancy to those who had tested HIV positive prior to the most recent pregnancy. Because HIV testing is closely linked to ANC registration, ANC registration was considered the main determinant of knowledge of HIV status. The factors which were associated with ANC registration were thus expected to be distally associated with knowledge of HIV status during pregnancy. Nonetheless chi-squared tests of association were run to determine the association of demographic and clinical participant characteristics with knowledge of HIV status during pregnancy. The same procedures described above were conducted, namely

1. Initial use of classical methods to investigate associations of variables with knowledge of HIV status during pregnancy
2. Multivariable analysis using factors that were found to be significantly associated (at  $p < 0.1$  level) with knowledge of HIV status
3. Checks for effect modification
4. Selection of variables for the final model

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#### **4.5.3 Data Analysis Methods for Six Weeks Clinic Attendance Data**

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Descriptive statistics were run for each of the variables. Chi squared tests of association were run to determine association between each of the variables with each other and with six week visit attendance. Univariable and multivariable logistic regression analyses were conducted to investigate factors associated with six week visit clinic attendance.

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### **4.6 SAMPLE SIZE AND JUSTIFICATION**

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The initial sample size for the cross-sectional survey, based on pragmatic considerations, was 300, where it was anticipated that 200 recently delivered women would be recruited from Harare and 100 from a rural site ( $n=300$  in total). It was estimated at the time the proposal

was written that 18% (n=54) will be HIV antibody positive (n= 36 in Harare and n=18 at rural site; n=54 in total). With 54 HIV positive participants the study would be able to measure rates of non-adherence to cotrimoxazole (in the longitudinal adherence study) with the following levels of precision: 33% (95% CI 21-48); 50% (95% CI 36-64%); 66% (95% CI 53-79%). Although with this sample size, the precision of estimates was suboptimal this was based on pragmatic considerations relating to availability of funding. Useful information was anticipated despite the imprecise estimates.

## **4.7 METHODS FOR QUALITATIVE DATA COLLECTION AND ANALYSIS**

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### **4.7.1 Justification for Incorporating the Qualitative Approach**

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Qualitative interviews are used to study the meaning of experience for different people. They elicit in-depth meaning and nuanced understanding of what or how individuals perceive and interpret phenomena and why people do what they do<sup>115</sup>. These methods were therefore appropriate for understanding the reasons why women had not registered for ANC, or why they had not attended the six week visit, or their experiences with adherence to cotrimoxazole prophylaxis.

### **4.7.2 Epistemological Position**

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The qualitative studies were conducted from an interpretative perspective, which means that the researcher seeks to understand how the participant understands and interprets her reality<sup>115</sup>. Another perspective taken in the qualitative interview is that of social constructivism, which means that there is realisation that there is co-construction of meaning during the interview process<sup>116-118</sup>: there is awareness that the interviewer is not a neutral observer, but by conducting the interview he or she participates in the social world that is being studied. It is therefore essential for the interviewer to be aware of his/her own values and interests and reflect on how s/he can affect the interview process and outcome, a process known as reflexivity. In addition, by recognising the co-construction of meaning during the interview process, as part of the reflexivity process care was taken to also focus on how the participant's circumstances might have shaped the narratives of the interview. It is well known that a participant can use the interview as a platform for creating an identity for herself<sup>116</sup>. For example, because women who had not registered for ANC knew that they were being interviewed for this very purpose, they may have had a sense of shame, or failure or

irresponsibility and might have felt pressured to use the interview to defend their roles or to create an identity of a responsible mother. Exploring the reasons behind a participant's chosen identity can help achieve greater understanding of the phenomenon under study.

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#### **4.7.3 Approach to Data Analysis and Justification**

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Qualitative data analysis was done according to thematic content analysis<sup>115</sup>. Thematic content analysis aims to report on key elements of participant accounts.

At the time of conception of the protocol the plan had been to analyse qualitative data using Framework analysis<sup>115</sup>. Framework analysis is an analysis strategy that is suited to research that has targeted questions, typically those used for policy-oriented research. As data collection and analysis unfolded it was clear that the participant data had broader themes and categories than initially envisaged. Therefore a more inductive approach was required i.e. a method that would focus more on themes that had emerged from participant data than does framework analysis, hence the use of thematic content analysis. The grounded theory approach, the prototype approach for analysis that discovers theory from data<sup>119</sup>, was not employed in this analysis because many of its elements are not possible to work with. For example grounded theory requires that you disregard findings from the published literature and focus only on participant data<sup>119</sup>. In this and many other studies it is difficult to work without doing a literature review as it guides the research question and is a criterion that funding agencies use for evaluating the merit of a study proposal.

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#### **4.7.4 Detailed Methods for Qualitative Data Collection and Analysis**

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All qualitative interviews were conducted using interview guides (Appendix 4). Interviews were conducted by the candidate in Shona and were digitally recorded. Soon after each interview detailed field notes (see sample in Appendix 5) were written, with reflection on how the interview had progressed and on emerging themes. Analysis thus began during the data collection phase. Themes which needed additional exploration were identified when writing field notes and were probed in subsequent interviews.

Interviews were transcribed verbatim, and translated into English by the candidate. After translation interview summaries were written for each interview, where a more analytic,

rather than descriptive, summary of the interview was made. The summary was written using information from the transcribed interview and from the field notes (see sample in Appendix 6). In the interview summary, comparisons were drawn between what the participant had said with what other participants had said, and questions were asked about potential reasons for discrepancies or deviant cases. Using themes that had emerged from interviews, as documented in interview summaries, a coding framework was developed, where a list of codes that were thought applicable to the data was generated. The list also contained codes which were considered analytical, rather than just descriptive. From each group of interviews, five transcripts were coded line by line on paper using the coding framework. Additional codes that were identified through line by line coding were added to the coding framework. The transcripts, field notes and interview summaries were then entered into NVIVO8, a computer package used for data management and retrieval. Coding of the transcripts was then done using the modified coding framework, keeping an eye to include any new codes which emerged. Analytic memos (see example in Appendix 7) were written for each theme that emerged from the data. During writing up, themes were illustrated using verbatim quotes.

## **CHAPTER 5: ANALYSIS OF POLICY AND IMPLEMENTATION PROCEDURES FOR COTRIMOXAZOLE PROPHYLAXIS IN ZIMBABWE**

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### **5.1 OVERVIEW**

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In this chapter I describe findings of an analysis of policy and implementation procedures for the provision of paediatric cotrimoxazole prophylaxis in Zimbabwe. A literature search of relevant documents describing the following was conducted: 1) the Zimbabwe policy and guidelines on paediatric cotrimoxazole prophylaxis, 2) implementation procedures for cotrimoxazole prophylaxis among HIV-exposed infants in Zimbabwe, 3) implementation procedures for the care of HIV infected women after delivery and 4) outcome indicators for paediatric cotrimoxazole prophylaxis and care of HIV positive women after delivery. In addition key informant interviews were held with a representative of MoHCW responsible for implementation of PMTCT and ARV rollout and a representative of the City of Harare Clinic Management responsible for Reproductive Health Services. In addition to questions covering the domains listed above, the key informants were asked about challenges faced with implementation. Also, a key informant interview was held with a representative from NatPharm, the company responsible for national drug distribution to get information on the drug distribution process, challenges faced and the adequacy of human and material resources. To obtain information on health care provider experiences with implementing cotrimoxazole prophylaxis, key informant interviews were held with two nurses at Mbare Clinic. Lastly, an assessment of cotrimoxazole stock levels at Mbare clinic during the period September 2010 to December 2011 was conducted.

Using information obtained from document review and key informant interviews a retrospective policy analysis was conducted. The analysis was done using a health policy framework called the policy triangle framework<sup>112,113</sup> as an analytical framework. This framework has four components to it, namely context, content, process and actors. It ensures that the policy analysis does not only focus on content of the policy, but includes all four components which are known to affect implementation outcomes.

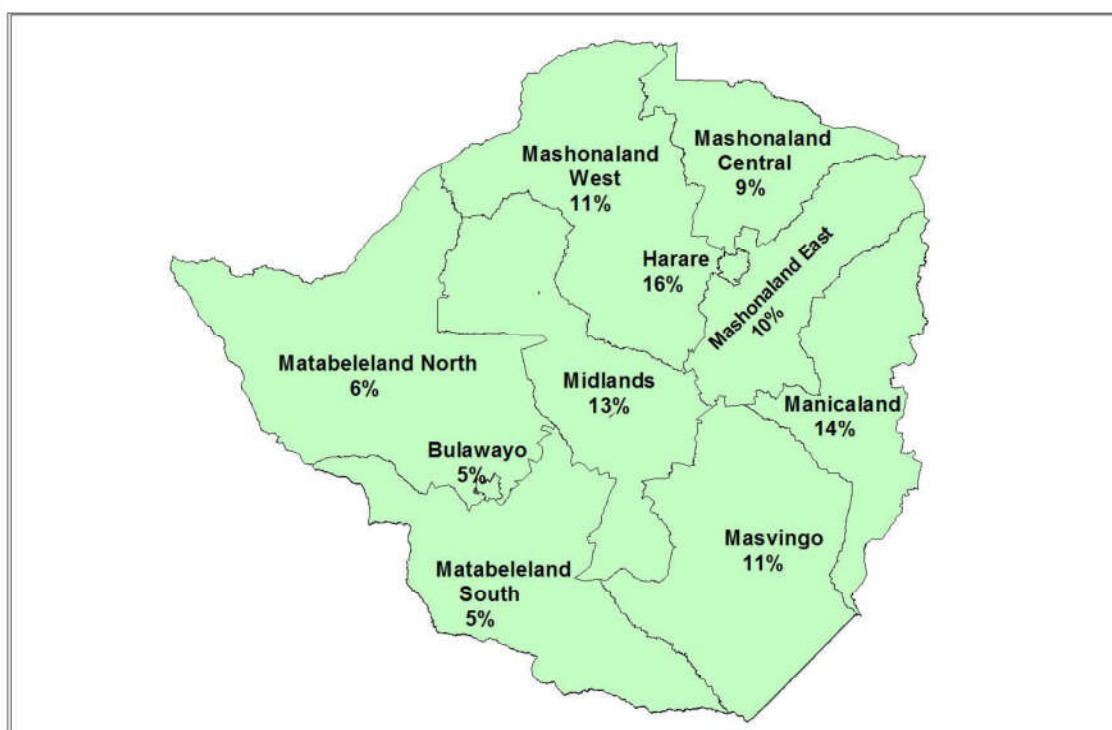
## 5.2 RESULTS

### 5.2.1 Context

This is a description of background factors that may have an effect on the implementation of paediatric cotrimoxazole prophylaxis.

Zimbabwe has a population of 12.97 million<sup>120</sup>. It is administratively divided into ten provinces (see figure 5.1 below). The most populous province is Harare, with a population of 2.1 million people contributing 16% to the total population in the country<sup>120</sup>.

**Figure 5.1: Distribution of the Zimbabwe Population by Province<sup>120</sup>**



#### 5.2.1.1 Zimbabwe's economic position and state of health services

Zimbabwe is classified by World Bank as a low income country with a GDP per capita of \$698 at the end of 2011<sup>121</sup>. The country is currently recovering from a politico-economic crisis that saw the decline of social services, including health care, during the period 1999-2008. The recovery started in 2009 after the signing of a Global Political Agreement between the three main political parties in Zimbabwe, which was followed by formation of a Government of National Unity in February 2009. The Zimbabwe dollar lost its value due to inflation, and introduction of multi-currency in 2009 helped stabilise the economy.

The economic problems, which peaked in 2008, resulted in various problems for the health care sector. There was a massive shortage of health care workers as they left the country to seek employment elsewhere. Vacancy levels in the public health sector in 2008 were at 69% for doctors, over 80% for midwives, over 63% for medical school lecturers and over 50% for pharmacy, radiology and laboratory personnel<sup>122</sup>. In addition there were shortages of medicines and equipment: availability of vital drugs in 2008 was between 29% and 58%. As a result of these shortages the quality of service provision in public health institutions significantly deteriorated; some government central hospitals closed for a period of several months.

After the formation of the Government of National Unity in 2009 there were urgent meetings to resuscitate the Zimbabwe health care system, starting with the formation of the 100-day plan to ‘kick-start’ the revival of the health care system, using funding from the Government of Zimbabwe and various donors<sup>123</sup>. This involved recruitment of staff, provision of retention allowances to key health care workers, repair of dilapidated health care facility infrastructure and recapitalisation of NatPharm, the national drug procurement and distribution company, among other things<sup>123</sup>. The health care system has been improving since that time. For the longer term, in 2009 the Ministry of Health and Child Welfare launched the National Health Strategy for Zimbabwe 2009-2013 whose major thrust is to improve equity and quality in health<sup>122</sup>.

#### **5.2.1.2 Structure of the Zimbabwe health care system**

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The Government of Zimbabwe subscribes to the Primary Health Care Approach through the Alma Ata declaration of 1978<sup>124</sup> and Ouagadougou declaration 2008<sup>125</sup> where it aims to ensure the provision of health care services to every person in the nation through a network of health care centres organised from primary level clinics to secondary, tertiary and central hospitals.

Primary level care consists of a network of clinics and community health workers and forms the first point of contact between the community and the formal health care system.

Community health workers are responsible for implementing various health promotion strategies with the support and supervision of health care workers at the clinic. Primary care clinics provide basic but comprehensive care including primary curative services, maternal and child health services such as antenatal care, delivery of uncomplicated births, family

planning and routine immunization of children. Primary level clinics refer complicated cases to district hospitals, which in turn refer to provincial hospitals which are themselves supported by central hospitals<sup>122</sup>.

In Harare, where the work for this PhD thesis was conducted, the set-up is somewhat different because there are no district or provincial hospitals. The public health care centres are managed by The City of Harare Department of Health Services. The network of City of Harare health care centres consist of 12 polyclinics which provide the full range of primary level services as above, 13 satellite clinics which provide all primary level services except delivery, and 6 family health clinics which only provide child health and community health services such as home visits<sup>126</sup>. The City authority also manages two infectious disease hospitals namely Beatrice Road Infectious Diseases Hospital and Wilkins Infectious Diseases Hospital. Any patient with serious/complicated conditions that cannot be managed at primary care level are referred directly to either an infectious disease hospital or a central hospital. HIV positive patients are referred to the two infectious disease hospitals for ART initiation.

#### National Drug Supplies

The procurement and distribution of drugs and other supplies for the public sector is done by NatPharm, a non-profit organisation that was formed through an act of parliament to improve efficiency in the supply of medicines. Zimbabwe has an essential drugs list<sup>127</sup> which gives guidance on drugs that are supposed to be stocked at the various levels of care. **C** drugs are required at primary care level and should be available at all levels of care; **B** and **A** drugs should be stocked at district and central hospitals only, although some B drugs may be held at a primary care centre on a named patient basis, for example for patients with chronic illnesses. Drugs are further classified according to priority: **V**-(vital) drugs are those that are considered to be life-saving; whose unavailability would cause serious harm. Effort should be made to keep them 100% available. **E**-(essential) drugs are given second priority and **N**-(necessary) drugs are still important but of lower priority. This classification is used in the prioritisation of scarce resources, and is the same list that guides NatPharm's procurements. Cotrimoxazole is classified as a category **C** and **V** drug which means it is expected to be 100% available at all levels of health care<sup>127</sup>.

#### Financing of the Zimbabwe health system

Funding for the health care system comes from the Government of Zimbabwe through taxation, donations from private voluntary organisations, donations from bilateral and multi-



lateral partners, health insurance, and direct out of pocket payments by patients<sup>122</sup>. During the period of politico-economic upheaval there was significant decline in bilateral funding to Zimbabwe, but the country continued to receive support from UN agencies such as WHO, UNICEF, UNFPA as well as European Union and the Global Fund for HIV and AIDS, TB and Malaria<sup>122</sup>, CDC and USAID.

In 2011 Zimbabwe launched The Health Transition Fund, a donor fund that is administered by UNICEF and is aimed at abolishing user fees for all women and children<sup>128</sup>.

#### Financing of City of Harare Health Services

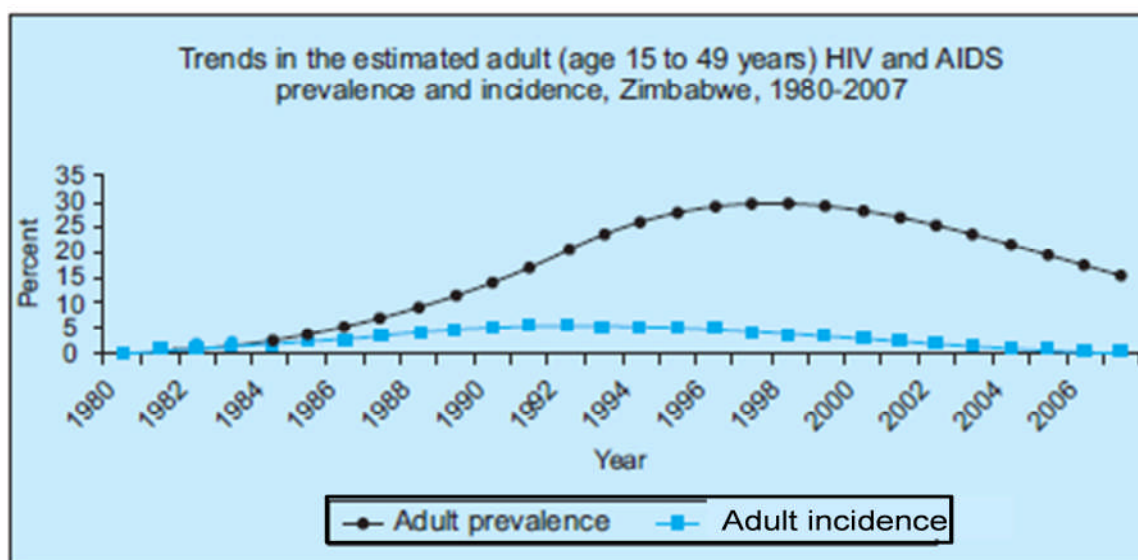
Since 1976 there has been an agreement that Government will fund 50% of recurrent and capital costs of City of Harare Health Services, but because of economic challenges this has not happened<sup>129</sup>. Since 1991 the government grant to City of Harare Health Services has been less than 1% of the City's total health expenditure<sup>129</sup>. City of Harare now relies on donors, user fees, and allocations from the municipality rates department. Since 2008 the International Committee of the Red Cross (ICRC) has provided 75% of City of Harare drugs, while the other 25% comes from other donors through NatPharm and the City of Harare's own purchases<sup>129</sup>.

City of Harare levies user fees for all patients except children under the age of 5, adults above the age of 65, and ART patients. Children 5-12 years pay \$3 and adults pay \$5. Maternity fees are currently charged at \$25, down from \$30 in 2011 and \$50 in 2009<sup>129</sup>. The maternity fees have been a source of contention between Government and City of Harare in recent years. In the first place, Government required that City of Harare reduce their fees from \$50 in 2009 to \$25. City of Harare complied, but later made representations that they could not manage with the reduced fees, and sought to revert to the \$50 in January 2012, a move which Government rejected<sup>130</sup>. Instead there have been calls from the Government for City of Harare to scrap maternity fees entirely. Government have already removed user fees for women and children in their own institutions. City of Harare have none the less resisted the directive to remove fees, maintaining that they cannot provide ANC and delivery services without them and wish to revert to the previous figure of \$50 because they are incurring deficits<sup>130,131</sup>.

### 5.2.1.3 HIV prevalence in Zimbabwe

According to the Zimbabwe Demographic and Health Survey (ZDHS 2010-2011) the HIV prevalence in Zimbabwe in the 15-49 age group is 15%, down from 18% in the 2005-06 ZDHS.<sup>43</sup> The prevalence among women of the same age group is 18%, compared to 12% among men. The highest prevalence of 29% is among women aged 35-39 years. Although Zimbabwe is among the highest HIV prevalence countries, it has registered a decline in prevalence from 29.3% in 1997, 26.5% in 2001, 23.2% in 2003, 19.4% in 2005 and 15.6% in 2007 in the 15-49 age groups<sup>122</sup>. Figure 5.2 illustrates this. It is believed that the adoption of safer sexual behaviour i.e. increased use of condoms and decrease in multiple partnering, is responsible for the decline<sup>132</sup>.

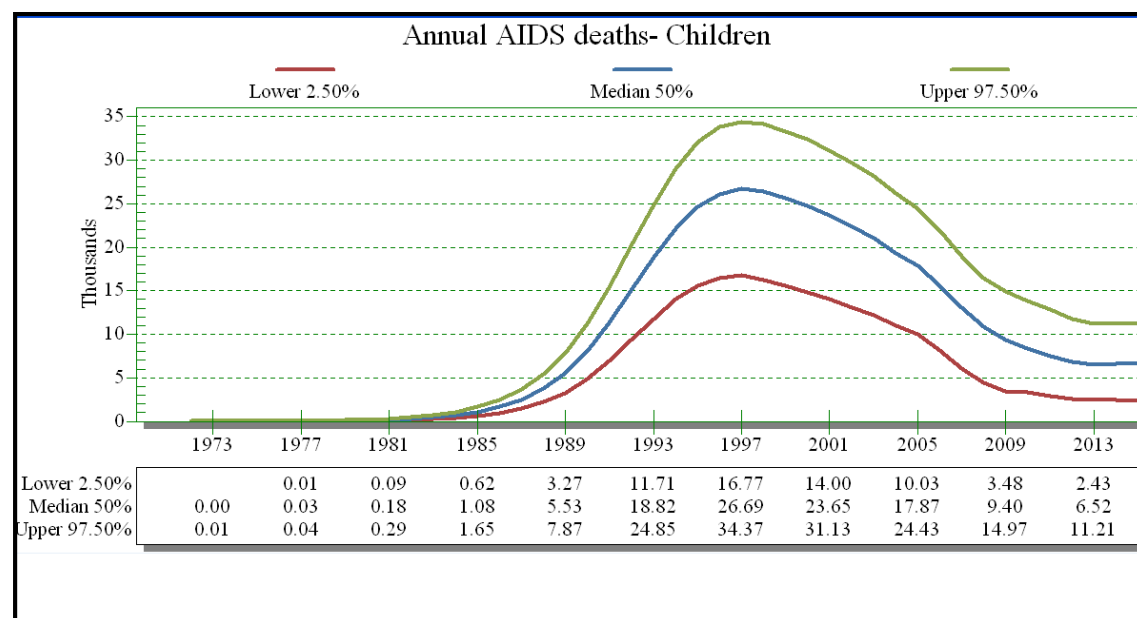
**Figure 5.2: Trends in Adult HIV prevalence and incidence in Zimbabwe, 1980-2007**<sup>132</sup>



In the 2010/11 ZDHS 90% of Zimbabwean women reported receiving antenatal care (ANC). However 34% of deliveries were reported to have occurred at home. The percentage mother to child transmission rates from modelled data in 2007 and 2009 respectively are 29% and 30%<sup>132</sup>. Another model, which looked at 12-month mother-to child transmission risks in 2008 (when single dose nevirapine was being implemented), showed a risk of 20.3%, which improved to 18% with modelled improvements in PMTCT uptake in 2009<sup>133</sup>. HIV prevalence among children aged 0-14 was 3.1%, 2.9% and 2.8% in 2009, 2010 and 2011 respectively<sup>132</sup>. In 2008 there were 107,388 children living with HIV; the number came down to 105,740 in 2009<sup>42</sup> but in 2011 it was estimated to be much higher, 138,642<sup>134</sup>. An estimated 26,687

children died of AIDS in 1997. Since then there have been sharp decreases in annual AIDS deaths as a result of scale-up of ART programs, fig 5.3<sup>42</sup>.

**Fig 5.3: Modelling of Trends in annual AIDS deaths of children<sup>42</sup>**



#### 5.2.1.4 Levels of cotrimoxazole prophylaxis

In Zimbabwe only 11% of children 0-14 years who needed cotrimoxazole received it in 2007<sup>29</sup>. This figure increased significantly to 34% in 2010<sup>31</sup>, but was still short of the MoHCW target of 80%. Within the City of Harare system, of 2, 279 women who tested HIV positive in 2009, 835 (36.6%) had their babies started on cotrimoxazole prophylaxis. This increased to 51.5% (1,797/3,491) in 2010<sup>135</sup>.

#### 5.2.1.5 Leadership in HIV/AIDS

There is government leadership and commitment to the response to HIV and AIDS; Government declared HIV and AIDS a national emergency in 2002 and is committed to achieving a national multi-sectoral response to the disease. To this end Government formed through an act of parliament, the National AIDS Council (NAC), the organisation that is tasked with coordinating the national multi-sectoral response to HIV.<sup>136</sup> The Government adopted the “three ones” principle which specifies that there should be “one national multi-sectoral HIV and AIDS strategic plan, one coordinating authority, and one national monitoring and evaluation system.”<sup>136,137</sup> Since its inception the activities of NAC have been guided by national plans or frameworks. In 2006-2010 it was guided by the Zimbabwe

National HIV and AIDS Strategic Plan (ZNASP 2006-2010)<sup>137</sup> which was superseded in 2011 by ZNASP 2011-2015<sup>136</sup>. PMTCT and retention of HIV-exposed babies and their mothers in care is strongly advocated for in both ZNASP 2006/10 and ZNASP 2011/15. The aim is to strengthen the national PMTCT program through strengthening the four prongs of PMTCT: 1) primary prevention, 2) prevention of unplanned pregnancies, 3) prevention of mother-to-child transmission, and 4) care and support for mothers and babies. The ZNASP is aligned to other regional and international frameworks that the Government of Zimbabwe is committed to, including: Millennium Development Goals, the Global Plan towards elimination of new HIV infections in children and keeping mothers alive, United Nations Declaration of Commitment (UNGASS Declaration), 2011 Political Declaration on HIV and AIDS, Maseru and Brazzaville Declarations, and the Maputo Plan of action<sup>136</sup>.

To fund the activities of the national response to HIV, the Government of Zimbabwe has established The National HIV and AIDS levy, that is anchored in the national tax system. The Government provides additional funding through direct government budget allocation. However this money is not sufficient to cover all the requirements of the national response to HIV so there is considerable reliance on external funding. In 2008, the government national budget allocation was US\$354,000; then it increased to US\$7.5 million in 2009. External funding from development partners and donors was US\$25 million in 2008 and US\$38 million in 2009. Collections for the AIDS levy amounted to US\$5.7 million in 2009 and increased to \$15.9 million in 2010<sup>136</sup>. Following the Paris declaration on harmonisation of funding mechanisms, the Government formed the Expanded Support Programme which was supported by many donors. Between 2007 and 2009 a total of US\$46 million was made available to the national HIV response through the Expanded Support Programme<sup>136</sup>.

The Ministry of Health and Child Welfare is responsible for implementing the national PMTCT program according to national targets. There is a dedicated unit within MoHCW, the AIDS and TB unit, which was tasked to provide guidance and oversight in the implementation of preventive, support and treatment services to the network of public health care institutions.

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### 5.2.2 Content

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This section describes the content of the policy and guidance for implementation of cotrimoxazole prophylaxis.

There is no stand-alone policy for cotrimoxazole prophylaxis but there are clear guidelines for its use in HIV-exposed infants and HIV positive children in the National PMTCT<sup>138</sup> and ART guidelines<sup>22</sup>. The guidelines are comprehensive and are based on WHO guidelines. They are clear about the need to prevent mother to child transmission and to keep both the mother and child in regular care. In summary, early booking of pregnancies before 14 weeks of pregnancy is recommended in order to ensure timely initiation of PMTCT activities. The guidelines instruct the health care worker to ask the HIV positive mother to bring the baby for HIV testing using a DNA PCR test at six weeks. The health care worker is also instructed to commence the HIV-exposed baby on cotrimoxazole prophylaxis at six weeks of age<sup>138</sup>. Cotrimoxazole prophylaxis should continue until HIV infection is excluded. If the baby is HIV positive, cotrimoxazole should be continued and the baby referred for ART.

The guidelines also instruct health care workers to ensure that all infants have their HIV exposure status determined at first contact with the health care system. To prevent loss to follow-up of HIV-exposed infants, the child health card has a section for documentation of HIV exposure status which health care workers must complete at time of delivery. HIV-exposed infants are supposed to be followed on a monthly basis. Also, to enhance follow-up infants should be entered into the HIV-exposed register which is intended to track the baby's HIV care.

The guidelines also provide clear guidance on the HIV care for HIV positive women: clinical staging according to WHO guidelines should be done; women in stages 3 or 4 should be prescribed cotrimoxazole prophylaxis and referred for ART, and women in stages 1 and 2 should be given ARV prophylaxis starting at 14 weeks. All HIV positive mothers should have a CD4 count test. The ART guidelines emphasise the need for regular 6-monthly assessment for ART eligibility for women who have previously been found to be ineligible<sup>22</sup>.

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### 5.2.3 Process

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This is a discussion of the process of policy development, communication of the policy to implementers, and the procedures conducted during implementation of the policy, including measures to ensure that the policy is followed.

#### **5.2.3.1. Policy development**

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According to the key informant from Ministry of Health and Child Welfare, their policies are guided by recommendations and guidelines from World Health Organisation, WHO. If there are new guidelines or recommendations, the Ministry of Health will meet with health care managers, implementers and their funding and implementing partners in order to reach consensus on how best to incorporate the new recommendations into practise.

#### **5.2.3.2 Policy implementation**

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Box 5.1 has information on procedures conducted by Ministry to ensure the implementation of cotrimoxazole prophylaxis, as given by the key informant from Ministry of Health.

**BOX 5.1: Key Informant Discussion with MoHCW Representative****Date of interview: 13 January 2011****The Policy on Cotrimoxazole Prophylaxis**

Although there may not be a stand-alone policy on cotrimoxazole prophylaxis, the national PMTCT and ART guidelines include specific guidance on the use of cotrimoxazole prophylaxis for HIV exposed infants. Various methods are employed to make health care workers aware of the guidelines:

- i) Training
- ii) Support and supervision visits-These are done through the existing Ministry structures at provincial or district level. The visits are not designed to provide support for cotrimoxazole prophylaxis alone but for the full range of health care services provided at health care centres. In addition, MoHCW also works with Implementing Partner Organisations (e.g. Elizabeth Glaser Paediatric AIDS Foundation (EGPAF), Kapnek Trust, ZAPP (Zimbabwe AIDS Prevention Project), and Organisation for Public Health Interventions and Development (Zimbabwe) (OPHID) who conduct support and supervision visits to the specific regions they support.
- iii) Monitoring and Evaluation Tools-The HIV exposed infant register asks for specific information on cotrimoxazole prophylaxis and so can serve as a reminder to the health care worker. Furthermore MoHCW have revised the mother held Child Health Card to capture information on cotrimoxazole prophylaxis for the HIV exposed baby.
- iv) For the private sector training is provided through the College of Primary Care Physicians. There was funding in Global Fund Round 8 to cover training in the private sector. In addition, although this is limited to those based in Harare, some private practitioners are academic lecturers at the UZ College of Health Sciences. MoHCW believes/hopes they practise what they teach.

**Implementing Targets**

It is MoHCW's desire to get all HIV-exposed infants on cotrimoxazole prophylaxis. However as this may not be practically achievable the current target is 80%, based WHO's goal of universal access. At time of interview the implementation rates were still unsatisfactory, with 2010 estimates indicating that 34% of HIV-exposed infants who needed cotrimoxazole prophylaxis received it (based on comparing the number of HIV positive women identified during pregnancy and the number of infants who have been prescribed cotrimoxazole prophylaxis).

**Challenges faced**

Not all women are tested for HIV, so there are some unidentified HIV-exposed infants. MoHCW statistics on cotrimoxazole prophylaxis coverage may not be accurate as they do not capture the HIV exposed babies who have not been identified. To solve this problem MoHCW is encouraging PITC for mothers who bring their babies to well-baby clinics. Babies born to mothers who test HIV positive at these clinics should also be treated as HIV

exposed infants who should be initiated on cotrimoxazole prophylaxis. To date, there are no statistics on the proportion of HIV exposed infants who are identified post-delivery.

The other challenge is that babies are lost to follow-up before the six-week post natal visit because their mothers do not attend. In many instances the women are in contact with the health care system before the six weeks. The Ministry of Health might need to think about allowing the prescription CTX before the six-week visit especially if it is foreseen that the mother might not be able to attend the six-week visit.

A further challenge is that PMTCT training is usually given only to health care workers in the ANC and maternity departments, without including nurses in the child health clinics. It is important to train the child health workers about cotrimoxazole prophylaxis because they see the babies on a monthly basis and are thus able to facilitate its optimum uptake.

#### **Any worries about microbial resistance as a result of cotrimoxazole prophylaxis?**

Although there is recognition that cotrimoxazole prophylaxis may increase microbial resistance, there have not been any active objections to its implementation in MoHCW.

#### **Procurement of Cotrimoxazole Prophylaxis Supplies**

MoHCW have asked funding partners to provide financial support to purchase the larger stocks required for universal cotrimoxazole prophylaxis. Although cotrimoxazole is not expensive, MoHCW sometimes has insufficient funds to procure it.

#### **Care of HIV Positive Women After Delivery**

There is a general feeling that many women diagnosed HIV positive during pregnancy are lost to follow up before they are assessed for ART eligibility.

*“You almost get the sense that most health care workers think that after that baby is born, the whole PMTCT issue is done.”*

*“I don’t have the maternal follow-up rates but my gut feeling is that we are missing out a lot of women. A lot of them are probably not enrolled in chronic HIV care.”*

To solve this problem, MoHCW have introduced the pre-ART register. Once a patient is entered into this register they are supposed to have scheduled appointments which will keep them engaged in care during the period before they become eligible for ART. An additional check is the HIV exposed infant register which collects information on the mother. In addition it is hoped that as mothers bring their babies for cotrimoxazole and extended nevirapine prophylaxis they will be kept engaged in care.

Provision of cotrimoxazole prophylaxis depends on good supply chain management system. Box 5.2 shows a summary of the interview that was conducted with the key informant from NatPharm, the national drug procurement and distribution company.



**BOX 5.2: Description of NatPharm and its Supply Procedures given by NatPharm key informant**

**Date of interview: 01 July 2010** (*see note at end of box*)

NatPharm is the national drug distribution company that has been set up to distribute drugs to the public health care institutions. It is headquartered in Harare and has several offices across the country. The Harare regional office distributes drugs and other supplies to three provinces namely Mashonaland Central, Mashonaland East and Harare Province. Most NatPharm stocks are procured by donors and NatPharm provides the storage and distribution services.

**Procedures for supplying drugs**

Each district is expected to place a monthly order with NatPharm. NatPharm have a calendar of activities; each district has specific days on which their orders are processed. However NatPharm also have a system for accepting urgent orders which can be processed on the same day they are received. The company generally delivers the supplies to the respective districts, although in some cases districts choose to collect their supplies themselves.

Supplies for City of Harare are ordered centrally through Beatrice Road Infectious Diseases Hospital. Individual clinics are then expected to order from the hospital.

All donated drugs are distributed to institutions or districts at no cost.

In addition to supplying according to requisitions, once every three months NatPharm distributes packages of drugs and supplies called primary care kits to primary health care centres in their districts. These kits contain the basic drug stocks that are needed in a primary health care facility. Like most drug stocks at NatPharm the kits are a donation. They were necessitated by shortages of qualified/motivated drug procurement personnel at primary care centres and are a way of ensuring that primary care centres do not run out of essential drug stocks.

**Current situation with cotrimoxazole stocks**

There are no problems with stock levels of both adult and paediatric formulations of cotrimoxazole.

*“As I am speaking right now I think we have seven donors for cotrimoxazole. We have to put in place measures to ensure that it does not expire on us.”*

**Challenges faced at NatPharm**

Sometimes there is no transport to deliver drugs and supplies to the districts. This problem has been eased by funding partners who have assisted with transport. Some institutions do not place their orders on time, they do urgent orders which disrupt the normal flow of activities and thus delay the processing of regular orders.

***Comment on length of time since key informant interview:** The candidate was kept up to date on NatPharm procedures and stock situation through regular attendance of national quarterly PMTCT forum meetings, where NATPHARM gives stock updates for all products that are used for PMTCT and HIV Care. Although it has been a long time since the key informant interview was held, the regular meeting reports showed that the situation (procedures and good supply of cotrimoxazole) was generally unchanged.*

### **5.2.3.3 Perspectives and experiences of policy implementers: Key informant interviews with nurses at Mbare Clinic**

The City of Harare Health Services operate using national guidelines and recommendations from Ministry of Health and Child Welfare. A key informant interview was held with a representative of the City of Harare Clinic Management, a nurse who is responsible for management of reproductive health services within City of Harare, who was based at Mbare Clinic. She was asked about 1) the process of receiving new policy and guidelines from Ministry of Health, 2) the process of informing health care workers at the clinic of new guidelines, and 3) her experience of implementation of paediatric cotrimoxazole at the clinic, including challenges faced.

#### Procedures for receiving new policy or new guidelines

When there are new policies or guidelines, MoHCW will normally call for training meetings or workshops and invite some nurses (typically one or two senior nurses from each clinic) and managers from City of Harare. These trained nurses will in turn conduct one-on-one on the job training sessions with nurses who were unable to attend the training meetings or workshops themselves. Ministry of Health normally provide training manuals and guidance documents that staff take back to the clinic to train their colleagues and use as reference material. New employees are given training on existing manuals during induction. Clinic managers also conduct spot checks/supervisory visits to support new staff and to check their understanding of existing guidelines. Another method of getting communication from MoHCW is through the district nursing officer. If there is new information the district nursing officer will bring it to the attention of clinic management who will in turn inform their colleagues at the clinic as above. In addition, clinic managers hold monthly meetings with the district nursing officer where policy and guideline issues may be discussed.

Because the clinic is busy, however, the process of training the nurses who did not themselves attend the training workshops is not usually done systematically. As a result there

are some staff who are not aware of new guidelines: “*Not everyone is aware. New staff may not be aware of the guidelines.*” **Clinic manager, head of reproductive health services**

Experience with implementation of cotrimoxazole prophylaxis: findings from three key informant interviews with nurses

Discussions with nurses revealed that they were generally aware of Ministry of Health guidelines on implementation of cotrimoxazole prophylaxis in children. Nurses stated that mothers were informed that they should bring the baby to the six-week post natal visit where the baby would be tested for HIV and commenced on cotrimoxazole. However there were instances where a nurse had incorrect information about a certain procedure, which might reflect the inadequacy of training as it is cascaded down from Ministry of Health to nurses who would not have attended formal training sessions. For example one nurse (the reproductive health services manager) said if a baby tested HIV negative at six weeks then there would be no need to keep giving cotrimoxazole yet the guidelines are clear about continued cotrimoxazole until exclusion of HIV infection, when the baby is no longer exposed to HIV through breast milk.

The same nurse was not aware of the procedures for follow-up of HIV positive women after delivery. While two nurses clearly described that HIV positive women who were not yet eligible for care were registered for follow-up at the clinic and given appointments to return for assessments on a six-monthly basis, the third nurse reported that there was no system for follow-up of HIV positive women: “*We are depending on the women to come back to us when they are not feeling well. We are always telling the women that if they have a problem they should come back.*” (**reproductive health services manager**) Not following protocols for the follow-up of women is likely to result in significant loss to follow-up of HIV infected women; something that was identified as a challenge by the Ministry of Health key informant.

Nurses also did not give uniform responses about the dosage of cotrimoxazole prophylaxis. The national guidelines (which are based on WHO guidelines which are shown on fig 2.1) clearly state that babies 0-6 months should be prescribed 2.5mls once daily, those 6 months to 3 years old should be given 5mls, and those over three years should be given 10mls. One of the nurses reported that babies should be started on 5mls, and another one correctly stated that they should be started at 2.5mls but she thought the higher dose should be commenced at

3 months. This may be another indication of the inadequacy of one-on-one on the job training of nurses who would not have attended the MoHCW training courses. Incorrect dosing was encountered in the group of women who were followed in the adherence study (Chapter 9).

Nurses generally felt that women who have had babies started on cotrimoxazole are keen to give it. This is what the Clinic Manager who also the head of sexual and reproductive health services within the City of Harare said: *“They are very motivated. The education we continue to give has helped.”* The challenge faced was that the women did not come back to the six-week visit. *“More than half of women are not coming. We don’t know why they are not coming.”* One nurse suspected that it was because participants have gone to rural areas. Nurses had seen many women who came to tell them that they were leaving to go to the rural areas before six weeks, and were asking for cotrimoxazole prophylaxis. The nurses would not prescribe it because the policy requires that they prescribe it at six weeks. Nurses felt this was a down side to the programme because the woman was likely to be lost to follow-up.

*“She can come and tell you that I am going to the rural areas, please can I have the cotrimoxazole. But we tell her to come back at six weeks, yet she is already telling you that she is going away. That woman will be lost unless she is able to transfer to another clinic.”* **Clinic manager, head of reproductive health services**

The head of the reproductive health services also stated that some HIV positive women default from the six-week visit because they are having trouble adjusting to their HIV diagnosis. Such women need additional counselling. There is a clinic department that is responsible for home follow-up of such women through the use of community health workers/health promoters. However the department is short-staffed and is overwhelmed with work, so is unable to conduct as many home visits as are required. Some patients give the wrong home address so when health promoters visit patients who have defaulted from their visits they are unable to find them. In general about 40 women register for ANC on a given ANC registration day and nurses suspect that five or six of these women give a false address. Nurses reported that this is because the women want to be cared for at Mbare Clinic but think they will be turned away if they give their correct non-Mbare addresses. Nurses reported that a customer service study that was conducted within City of Harare found that some women prefer Mbare Clinic and do not go to the clinics in their own neighbourhoods because the nurses in those clinics are rude. Some have said they prefer Mbare Clinic because they

always have drugs in stock. Nurses believe most of this is influenced by information shared in the communities; patients then seek care according to what they would have heard from their friends or family.

When women come to the clinic at the six-week visit, they are first seen at the maternity clinic, and then referred to the chronic disease clinic which is housed within outpatients department where the baby will be registered in the HIV-exposed infant register and have cotrimoxazole prescribed. Because prescription of cotrimoxazole happens in a separate building, maternity nurses worried that women might be lost to follow-up when referred from one building to another, particularly because of the long waiting times to be seen at the chronic diseases clinic. *“That clinic is busy. Some may not want to join the queue.” (nurse-midwife at Mbare Clinic).* Women are instructed to bring the baby to Mbare clinic on a monthly basis; they would first be expected to take the baby to the Family Health Services Clinic where growth monitoring and immunization services were offered. The woman would then be expected to go to the chronic disease clinic for cotrimoxazole prescription refills. Nurses worried that this non-integrated approach might discourage women as they had to wait in long queues at both clinics. However nurses thought this approach served to protect women against unwanted HIV disclosure: the set-up at the family health services clinic does not offer privacy; babies are weighed, given their immunizations and the mother asked questions about the baby’s well-being in the same room where all mothers will be waiting. If HIV care were to be given in this setting the mother’s HIV status would be disclosed to all the other mothers in the room. Because of large numbers of attendees seen at the family health services clinic, private one-on-one consultations are not manageable.

The other challenge nurses reported was that women generally register for ANC very late in their pregnancy, sometimes as late as 36-37 weeks. This is despite encouragement to register as early as three months gestation. Some women do not register at all; they will just come to deliver at the clinic. Such women will have an unknown HIV status. Nurses said they are supposed to offer HIV testing during labour or soon after delivery, but in practise this is difficult: *“The clinic is busy. We are not always able to test those women in the labour ward. We miss most of them.” (nurse-midwife at Mbare Clinic).*

The major challenge nurses reported was with stock-outages of cotrimoxazole. Nurses reported that there were many instances when cotrimoxazole stocks were out for long periods

at a time. The clinic obtains its supplies from Beatrice Road Infectious Diseases Hospital (BRIDH) where the main City of Harare pharmacy is located. Nurses reported that it can take up to a month to get the orders back because BRIDH are very busy. They worried that women might not afford the cost of cotrimoxazole in private pharmacies. *“If only we could find a sponsor or donor to give us cotrimoxazole so that we do not run out of cotrimoxazole stocks,” (Sister-in-charge, Mbare Clinic).* Ironically, the key informant at NatPharm reported that they had *“seven donors for cotrimoxazole”* and were having to *“put in place measures to ensure that it does not expire on us.”* This indicates that Harare City Health has challenges with managing the supply chain from NatPharm to the main pharmacy at BRIDH hospital and then to the clinics.

One of the objectives when this project was first designed was to conduct an audit of drug orders that had been generated at the clinic and submitted to BRIDH and then to NatPharm. It was not possible to do this because the nurses kept saying they were busy and they were not able to give us information on purchase requests they had generated and submitted to BRIDH. It was clear that the clinic nurses were having challenges managing the supply chain, mainly because they were busy and possibly because of lack of training in supply chain management. A report on the City of Harare website that was inserted by the pharmacy department identified that there was need for training of nurses on supply chain management, and that logistical challenges prevented optimum performance of the main pharmacy at BRIDH, fig 5.4.

Figure 5.4 Extract from City of Harare Website<sup>126</sup>

#### About The Pharmacy Department

The department has a central pharmacy that is located at Beatrice Road Infectious Diseases hospital and has the responsibility to purchase, supply and monitor the drugs and medical sundries for the department. Thanks largely to the support the department has been receiving from the International Committee of the Red Cross and the German government and the City of Munich, the city averaged 70% availability of essential drugs and over 90% of vital drugs in 2008 and 2009. The supply of sundry materials also improved.

While the department welcomes and appreciates the support it received from partners, this support will not be in perpetuity and the city needs to find a more sustainable funding arrangement. There is need to drastically improve our stock management systems. Firstly, there is need to computerise the central pharmacy at Beatrice Road Hospital. All the clinics and hospitals dispensaries need to be computerised and networked to the central pharmacy. There is need to continuously train all staff in stock management. The department also faces considerable challenges in terms of logistics. Currently the department uses the same pool vehicles used for linen, clinic waste and other logistics to ferry drugs and medical sundries. The pharmacy moves enough quantities of drugs and sundries to justify a lorry dedicated for that purpose.

Accessed from

<http://www.hararecity.co.zw/index.php/departments/health/pharmacy> on 14 March 2013

#### **5.2.3.4 Results of the assessment of cotrimoxazole suspension stock levels**

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The dispensary is located in the Outpatients Clinic building. It is a secure room which has double-locking doors and a lockable security screen to prevent unauthorised entry. It is manned by nurses. At any time there is a nurse who is in charge of ordering, storage and distribution of drugs to all departments in the clinic. Nurses take on this role on a rotational basis, with one person acting in this capacity for about three months.

There is a stock card for all the drugs that are kept at the clinic, including cotrimoxazole suspension. Study staff noted that in general, the minimum stock is not recorded on the stock cards.

Three assessments for stocks of cotrimoxazole suspension were made: on 27 Sep 2010, 07 April 2011 and 07 December 2011.

##### ***27 September 2010 Assessment***

There were only sixteen bottles of 50mls each at the time of assessment. Nurses reported that because cotrimoxazole stocks were so low, they had stopped prescribing it for acute infections and were limiting its use to cotrimoxazole prophylaxis. A requisition for additional supplies of the drug had been raised on 10 September 2010, but had only been submitted to the BRIDH on 24 September. It was not clear why there had been this delay. The nurses had been given assurance that they would receive a consignment from BRIDH by 29<sup>th</sup> of September.

##### ***27 April 2011 Assessment***

There were 680 units of 50mls each in stock. Seven hundred units had been received from ICRC on the previous day (26 April 2011). Before receipt of this consignment, cotrimoxazole had been out of stock since 22 March 2011. At the time of assessment, a requisition (in which cotrimoxazole suspension was one of the requested items) had been submitted to BRIDH on 31 March 2011 as an urgent request. It had not yet been received from BRIDH and it was not known when supplies were expected.



### **07 December 2011 Assessment**

On this day there were 423 bottles of 60ml cotrimoxazole in stock. A review of records from 27 April 2011, when the previous stock assessment was made, showed that cotrimoxazole went out of stock on 20 May 2011, and the next supply was received on 07 June 2011. It again went out stock on 29 July 2011, and on 02 August the clinic asked for 10 bottles of cotrimoxazole from another City of Harare Clinic, Matapi Clinic. All the bottles were dispensed on the same day and cotrimoxazole was out of stock again. The clinic then received 50 bottles from another clinic on 03 August, and on 04 August they received a consignment of 400 bottles from ICRC.

### **5.2.4 Actors**

Document review, key informant interviews and assessment of stock levels at the clinic revealed that there were many stakeholders involved in the implementation of cotrimoxazole prophylaxis. Table 5.1 shows a list of stakeholders, the level of importance they attached to implementation of cotrimoxazole prophylaxis and kind of influence they had on implementation. Of note, the actors were included only at organisational level. However the policy analysis would have benefited from an examination of the contribution of key individuals to policy. Examination of these individuals required time and financial resources to study their values and motivations, which was difficult to do with the limited PhD fellowship funding.

**Table 5.1: Cotrimoxazole Prophylaxis Stakeholder Analysis**

<b>Stakeholder</b>	<b>Level of importance attached to implementation</b>	<b>Level of influence</b>	<b>Limitations of the influence</b>
Government of Zimbabwe through National AIDS Council	High importance attached to response to HIV issues. This is mainly because of the Government's own values where there is a great drive to reduce AIDS-related deaths following the declaration of HIV/AIDS as a national emergency.	High influence at macro level, particularly in mandates to MoHCW.  High influence on day to day implementation activities; funding for drug supplies allows implementation	High influence at macro-level and at micro level (through provision of funding) but no direct supervision of health care workers so little influence on performance of individual health care workers.

Stakeholder	Level of importance attached to implementation	Level of influence	Limitations of the influence
Ministry of Health and Child Welfare	Ministry of Health attach a lot of importance to cotrimoxazole prophylaxis. They initiated and developed the policy and guidelines and communicated it to the implementers.	High influence at macro level as they have mandated/directed the nationwide adoption of guidelines.  Medium influence on day-to-day activities at clinic level through support visits	Influence is mainly at macro-level, little influence on performance of individual health care workers, who are the implementers on the ground.
Bilateral and multi-lateral donors	High importance attached to alleviating HIV disease burden and reduction of mortality	High influence at macro level; funding enables implementation of activities.  Also high influence at clinic level as donated supplies enable implementation	Influence is mainly at macro-level, with no influence on the performance of health care workers, who are the implementers on the ground.
Implementing partners working with MoHCW (These are non-governmental organisations that have set-out to help MoHCW implement PMTCT processes in selected districts across the country) <ul style="list-style-type: none"> <li>• EGPAF<sup>1</sup></li> <li>• Kapnek<sup>2</sup> Trust</li> <li>• ZAPP<sup>3</sup></li> <li>• OPHID<sup>4</sup></li> <li>• And others</li> </ul>	High importance. Work together with MoHCW in crafting the policy and guidelines. Help MoHCW in printing and disseminating guideline and promotional materials	High influence at macro level.  High influence on day-to-day activities in the areas where they provide support visits.  Medium/low direct influence at Mbare Clinic because they have no direct influence on day to day activities.	The influence of these implementing partners is limited to the districts in which they work they have no influence on day to day activities in districts where they are not located.

Stakeholder	Level of importance attached to implementation	Level of influence	Limitations of the influence
NatPharm	High importance attached to ensuring uninterrupted drug supplies	High influence on day-to-day activities; drug shortages prevent implementation	No direct supervision of pharmacy staff at City of Harare health care centres, so limited influence on the stock management roles at City of Harare Clinics.
BRIDH Pharmacy	Not clear; not directly researched (see explanation in section 5.2.3.3)	High influence on day-to-day activities; drug shortages at clinic prevent implementation	Not clear, not directly researched (see explanation in section 5.2.3.3).
Mbare clinic nurses	High importance attached to cotrimoxazole prophylaxis	High influence on day-to-day implementation of cotrimoxazole	Influence limited mainly to Mbare Clinic attendees.

1- Elizabeth Glazer Paediatric AIDS Foundation

2-Kapnek Trust

3-ZAPP-Zimbabwe AIDS Prevention Project

4-OPHID- Organisation for Public Health Interventions and Development (Zimbabwe)

### 5.3 SHORT DISCUSSION ON POLICY ANALYSIS

There is Government commitment to respond to HIV issues in the country. Ministry of Health and Child Welfare attach great importance to cotrimoxazole prophylaxis for HIV exposed infants; together with partners they came up with guidelines for implementation of cotrimoxazole and circulated them to implementers, based on WHO guidelines. Bilateral and multi-lateral donors also value this intervention and have donated drug/funds towards it: there were more than adequate supplies of cotrimoxazole in the country during the time of study. What is clear from this policy analysis is that the commitment and support at national and international level needs to be extended to clinic level in order to ensure appropriate implementation. The economic challenges facing the country have resulted in limited support of City of Harare health services by Government, which in turn has affected the City's ability to hire adequate numbers of trained staff. That staff were overwhelmed with work provided the greatest barrier to policy implementation: staff did not have time to offer HIV testing to women who came with unknown HIV status during delivery, which is a missed opportunity

for a significant number of women given that only 77% of women registered for ANC (Chapter 6). The other challenge was the inadequacy of staff training on policy issues. Ministry of Health trains a limited number of staff who are expected to in turn train their colleagues on site. In practise this is difficult in a busy clinic/short-staffed clinic, resulting in some staff doing the work without full knowledge of the guidelines they are implementing, which in turn will compromise the quality of the work. There were serious supply-chain management issues: the country had more than adequate supplies of cotrimoxazole yet the clinic experienced four cotrimoxazole stock outages during the course of the field work for the study (September 2010 to December 2011). In summary, there was commitment at national and international level but without adequate follow-up to ensure site capacity to implement policy procedures resulting in sub-optimal implementation. A list of challenges that were identified during the policy study is given in table 5.2 below.

**Table 5.2: List of challenges identified in the policy study**

<b>Policy Analysis Component</b>	<b>Source of data</b>	<b>Key challenges</b>
<b>Context</b>	Findings for this component mainly came from review of official documents and the candidate's prior knowledge.	Economic problems in the country resulting in <ul style="list-style-type: none"> <li>• Inadequate funding for the national HIV/AIDS response</li> <li>• Failure of Government to fund City of Harare Health Services, resulting in City of Harare's strong reliance on user fees</li> <li>• High HIV prevalence and high rates of mother-to-child transmission of HIV in Zimbabwe</li> </ul>
<b>Content</b>	Findings for this component mainly came from review of official documents.	Challenges with the content of the policy will be stated below as they were brought to light in key informant interviews under the "process" component.
<b>Process</b>	Findings for this component mainly came from key informant interviews.	<b>Ministry of Health Key informant</b> <ul style="list-style-type: none"> <li>• Unidentified HIV-exposed infants because some women are not tested during pregnancy statistics on cotrimoxazole prophylaxis uptake are an overestimate</li> <li>• Loss to follow-up of infants before the six-week visit (when cotrimoxazole prophylaxis should be initiated)</li> <li>• Training gaps: PMTCT training often does not include nurses who work in the child health clinics (child health nurses see babies on a monthly basis and are thus able to facilitate optimum uptake of</li> </ul>

		<p>cotrimoxazole prophylaxis)</p> <ul style="list-style-type: none"> <li>• Reliance on external funders for adequate supplies of cotrimoxazole</li> <li>• Loss to follow-up of HIV positive women after delivery</li> </ul> <p><b>NatPharm Key Informant</b></p> <ul style="list-style-type: none"> <li>• Transport problems preventing smooth delivery of supplies to health care centres</li> <li>• Poor supply chain management at health care centres</li> </ul> <p><b>Key informant interviews with nurses</b></p> <ul style="list-style-type: none"> <li>• Training not optimally cascaded down from Ministry of Health to implementing health care workers some health care workers are not aware of the guidelines on cotrimoxazole prophylaxis</li> <li>• Non-attendance of the six-week visit (the visit when cotrimoxazole prophylaxis should be initiated).</li> <li>• Travel of mothers to rural areas before the six-week visit; requests for cotrimoxazole prophylaxis before the six-week visit but nurses are bound by policy which stipulates prescription at six weeks</li> <li>• Understaffing of clinic departments; long queues and long waiting times</li> <li>• False home addresses given by clinic attendees</li> <li>• Non-integrated services (PMTCT and HIV care services provided at separate clinic from child health services clinic)</li> <li>• Delayed (sometimes none) registration for antenatal care leads to challenge of unidentified HIV exposed babies</li> <li>• Workload challenges prevent HIV testing of women of unknown HIV status at time of delivery</li> <li>• Stock-outs of cotrimoxazole</li> </ul> <p><b>Cotrimoxazole stock assessments</b></p> <ul style="list-style-type: none"> <li>• Frequent cotrimoxazole stock-outs</li> <li>• Poor supply chain management</li> </ul>
<b>Actors</b>	Findings for this component came from review of official documents, key informant interviews and candidate's prior knowledge.	Each actor organisation had limitations to their power which prevented optimum implementation of cotrimoxazole prophylaxis.

These findings will be discussed in more detail in the discussion chapter.

## **CHAPTER 6: PATIENT SURVEY RESULTS**

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### **6.1 OVERVIEW**

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In this chapter I report on the findings of the patient cross-sectional survey. This survey was conducted among women residents of Mbare who had just delivered babies. Eligible women were recruited from the post-natal wards at Edith Opperman Maternity Clinic, and from the post-natal clinics at Mbare clinic (mainly at day ten postnatally), between September 2009 and February 2010. Those who were willing to participate first gave written informed consent before completing an interviewer-administered questionnaire. The questionnaire sought information on demographic and clinical characteristics of participants and the care they received during pregnancy, particularly the timing of ANC and testing for HIV. The questionnaires were completed by a trained nurse-counsellor. The quantitative survey data was analysed using Stata Version 9.0.

### **6.2 DEMOGRAPHIC AND CLINICAL CHARACTERISTICS OF PARTICIPANTS**

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299 participants (54% of women who delivered at Mbare Clinic during the recruitment period) were interviewed soon after delivery (either while they were still in the postnatal ward or at the 10-day postnatal clinic) between 21 September 2010 and 10 February 2011. The participation rate of 54% is considered low and could be a source of bias if there are differences between participators and non-participators. The rate was so low because participants in the postnatal wards often refused to participate, often saying they were in too much pain to participate. Recruitment from the 10-day postnatal visit was introduced to get round this problem; at that clinic non-participators often said they had no time as they needed to rush back home. In addition, some women might not have attended the 10-day visit. No data on characteristics of non-participators were collected; however comparison of survey participant characteristics and characteristics of participants in the clinic record review (Chapter 8, section 8.2) revealed a similarity in the two participant groups, suggesting that survey participants were representative of women delivering at Mbare Clinic.

See table 6.1 for demographic and clinical characteristics of participants. Participant mean age in years was 26.1 (95% confidence interval 25.4-26.7). The majority (64.5%) had

delivered at Edith Opperman Clinic, and a quarter (24.7%) at Harare Central Hospital. Of note, 20 (6.8%) of participants had delivered at home.

207 (69.2%) of women had been educated to O Level. Only 30% participants earned their own income, with an average monthly income of US\$33.76 (95% CI 25.08-42.45). Most (89.3%) women were married, 20 (6.7%) were divorced. The majority of partners/husbands (91.8%) earned an income. Five women did not know the amount of money earned by their partners. The mean monthly income for partners was \$165.86 (\$149.36-\$182.35), and mean household income was \$180.89 (\$161.74-\$200.03).

About half (47.8%) the women lived in rented accommodation, with an average of 2.4 (95% CI 2.3-2.6) people living per room.

The mean number of children per woman was 2.27 (2.13-2.42). 8.7% and 13.1% had a history of children who had died or who had miscarried respectively.

145 (48.5%) of pregnancies were unplanned. Of the participants with unplanned pregnancies, 74 (51.0%) were not using any contraception. Of the 71 women who were using contraception when they got pregnant, 55 (77.5%) were on the oral contraceptive pill, 8 were on the injectable contraceptive and the other 8 reported that they were using condoms.

104 women reported that they had worried when they discovered that they were pregnant. The main reasons for worrying were financial implications of a new baby (45 women); some women just did not want another child (54 women). 18 women said they worried about their own health; this was strongly associated with HIV status (25.7% of HIV positive women reported this compared to 3.0% of HIV negative women,  $p<0.001$ ).



**Table 6.1: Demographic and Clinical Characteristics of participants**

Characteristics	N (%)	Characteristics	N (%)
Clinic of delivery		Food security	
Edith Opperman	191 (64.5)	No food problems	217 (73.1)
Harare Hospital	73 (24.7)	Food problems	80 (26.9)
Home delivery	20 (6.8)	Whether own income earned	
Other	12 (4.0)	Yes	90 (30.2)
Participant age (years)		No	208 (69.8)
15-19	41 (13.9)	Marital Status	
20-24	100 (33.0)	Married	267 (89.3)
25-30	86 (29.1)	Divorced	20 (6.7)
30-34	38 (12.9)	Widow	3 (1.0)
35-39	27 (9.1)	Single	9 (3.0)
40 and above	3 (1.0)	Whether partner earned money	
Religion		Yes	245 (91.8)
Roman Catholic	43 (14.4)	No	22 (8.2)
Anglican	18 (6.0)	Combined household income (US\$/month)	
Methodist	25 (8.4)	None	34 (11.7)
Baptist	2 (0.7)	1-50	24 (8.28)
Presbyterian	1 (0.3)	51-100	55 (18.97)
Seventh Day	4 (1.3)	101-200	103 (35.52)
Apostolic	84 (28.1)	201-300	31 (10.69)
Pentecostal	82 (27.4)	301-400	15 (5.17)
Moslem	1 (0.3)	401-500	10 (3.45)
Traditional	1 (0.3)	>500	18 (6.21)
No religion	12 (4.0)	Financial support	
Other	26 (8.7)	No support	50 (16.7)
Education		Has support	249 (83.3)
Primary	20 (6.7)	Number of children	
Junior Certificate	59 (19.7)	1	99 (33.1)
O level	207 (69.2)	2	91 (30.4)
A level	9 (3.0)	3	60 (20.1)
Tertiary	4 (1.3)	4	31 (10.4)
Tenancy		5	14 (4.7)
House owner	32 (10.7)	6	3 (1.0)
Lodger	143 (47.8)	7	1 (0.33)
Family member	121 (40.5)	Whether pregnancy was planned	
Other	3 (1.0)	No	145 (48.5)
Type of toilet		Yes	154 (51.5)
Flush toilet	282 (94.3)	Feelings about pregnancy	
Own Blair* toilet	12 (4.0)	Happy	184 (61.5)
Neighbour's Blair	5 (1.7)	Neither happy/troubled	11 (3.7)
		Troubled	104 (34.8)

\*Blair toilet is similar to a pit latrine

### Association of factors with each other

There was strong association of socioeconomic variables with each other e.g. availability of financial support was associated with household income,  $p=0.008$ : 69.0% of women who had household incomes of \$0-\$50 received financial support from someone, compared to 83.6%, 89.3%, and 86.5% among those with household incomes of \$51-\$100, \$101-\$200, and >\$200 respectively. There was evidence of a strong association between tenancy and availability of financial support; 90.4% of people who rented accommodation were had financial support, compared to 75.0% and 76.9% for house owners and people who lived with family/relatives respectively. 14.3% of married women had household incomes of \$0-\$50, compared to 60% in those who were divorced,  $p<0.001$ . Women who had household incomes of \$50 or less were less likely to have planned pregnancies than those with higher incomes (34% compared with >50% for each of the higher categories),  $p=0.03$ .

Household income was not associated with parity; neither was it associated with history of miscarriage.

Out of 154 women who planned their pregnancies, 75 (48.7%) and 12 (7.8%) discovered that they were pregnant within the first month of pregnancy and after the first trimester respectively, compared with 28.3% and 16.6% among women who did not plan their pregnancies,  $p<0.001$ . Chi-squared tests of association showed no evidence of an association between timing of discovery of pregnancy and timing of ANC registration,  $p=0.28$ . There was a strong association,  $p<0.001$  between whether the pregnancy was planned and how the woman felt about the pregnancy: 68.3% of women who did not plan their pregnancy were worried when they discovered that they were pregnant, compared with only 3.2% among those who had planned their pregnancies.

There was strong evidence of association,  $p=0.05$ , between history of a child who died and education: 13.9% of those who did not reach ordinary level education had a child who died, compared to 6.8% among those who had reached ordinary level education.

### **6.3 ANC REGISTRATION AND ASSOCIATED FACTORS**

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229 women (76.6%, 95% CI 72%-81%) registered for ANC. Of women who did not register for ANC, 59 (85.5%) reported that they did not register because they could not afford the ANC registration fees. Four women reported that they did not think it important to seek ANC; two were not allowed to seek ANC by their husbands, and one woman's religion did

not allow her. The mean number of weeks gestation at time of registration was 29.5 (95% CI 28.6-30.4). Table 6.2 shows the times at which women registered.

**Table 6.2: Gestation weeks at time of ANC registration**

<b>Gestation weeks at time of ANC registration</b>	<b>N (%)</b>	<b>Cumulative %</b>
<b>5-8</b>	2 (0.95)	0.95
<b>9-12</b>	3 (1.43)	2.38
<b>13-16</b>	6 (2.86)	5.24
<b>17-20</b>	12 (5.71)	10.95
<b>21-24</b>	16 (7.62)	18.57
<b>25-28</b>	39 (18.57)	37.14
<b>29-32</b>	65 (30.95)	68.10
<b>33-36</b>	45 (21.43)	89.52
<b>37+</b>	22 (10.48)	100.00

208 (90.8%) women who had registered for ANC had more than one ANC visit, i.e. returned to the clinic for at least one ANC visit after the initial ANC registration visit. Of 21 women who did not return to a health care facility after registration, 9 said they had had no money. These are women who would have initially registered at a rural clinic and then relocated to Harare. They are expected to re-register and pay the registration fee when they transfer to Mbare Clinic; and they reported that they could not afford to do so. The other 8 participants reported that they had registered so late that they delivered before they were due for their next appointment. Only one woman reported that she did not think it important to have return ANC visits.

There was evidence of decreased levels of ANC registration with most factors which were measures/proxy measures of financial stress (Table 6.3). There was a 23% decrease in ANC registration associated with a unit increase in number of people living in a room, odds ratio 0.77 (95% CI 0.61-0.96). The odds of registering for ANC increased by 3% for every \$10 increase in household income, OR 1.03 (1.01-1.05),  $p=0.008$ . In addition, women who had financial support were twice as likely to register for ANC. Of note, some variables which might reflect poverty in other settings were positively associated with ANC registration, which needs caution in interpreting. For example, lodgers and family members were more

likely to seek ANC registration than house owners. Because Mbare is such a poor community, house ownership is not necessarily an indication of good financial standing as most accommodation in Mbare (particularly the flats) is of a very poor standard; it was allocated to bachelors during the colonial period and has been passed along as an inheritance within families. On the other hand, having rented accommodation might indicate an ability to pay rent and therefore implies possession of a regular income. Indeed section 6.3 above shows that women who lived in rented accommodation had better financial support than those who owned the accommodation they lived in. Therefore the house ownership variable is not a good indicator of financial standing, particularly in the ultra-poor community of Mbare. The same uncertainty is seen with type of toilets; the older accommodation mainly has flush toilets, but some of the newer houses (which are considered to be generally of a better standard than the old flats) have not yet had running water installed and therefore use Blair toilets.

Attention was therefore focused on the variables that were thought to clearly indicate the economic position of individuals, for example household income, food security and availability of financial support.

**Table 6.3: Univariable analysis of association of factors with ANC registration**

Characteristics	N (%)	N (%) Registered for ANC	Odds ratio (95% CI)	p
<b>Age</b>				
15-24	141 (47.8)	107 (75.9)	1	
25-30	86 (29.1)	60 (69.8)	0.73 (0.40-1.34)	0.31
30+	68 (23.0)	58 (85.3)	1.84 (0.85-4.00)	0.12
<b>Religion</b>				
Non-apostolic	215 (71.9)	161 (74.9)	1	
Apostolic	84 (28.1)	68 (80.9)	1.43 (0.76-2.67)	0.27
<b>Education</b>				
Did not reach O Level	79 (26.4)	54 (68.3)	1	
Reached O Level	220 (73.6)	175 (79.6)	1.80 (1.01-3.20)	0.05
<b>Tenancy</b>				
House owner	32 (10.7)	20 (62.5)	1	
Lodger	146 (47.8)	115 (78.8)	2.23 (0.98-5.04)	0.05
Family member	121 (40.5)	94 (77.7)	2.09 (0.91-4.81)	0.08
<b>Type of toilet</b>				
Flush toilet	282 (94.3)	214 (75.9)	1	
Blair toilet	17 (5.7)	15 (88.2)	2.38 (0.53-10.69)	0.26
<b>Source of water</b>				

Characteristics	N (%)	N (%) Registered for ANC	Odds ratio (95% CI)	p
Shared tap	218 (72.9)	166 (76.1)	1	
Unshared tap	60 (20.1)	48 (80.0)	1.25 (0.62-2.54)	0.53
Other	21 (7.0)	15 (71.4)	0.78 (0.29-2.12)	0.63
Food security				
No food problems	217 (73.1)	173 (79.7)	1	
Food problems	80 (26.9)	54 (67.5)	0.53 (0.30-0.94)	0.03
Income				
Earns an income	90 (30.2)	64 (71.1)	1	
No own income	208 (69.8)	164 (78.5)	1.51 (0.86-2.66)	0.15
Marital Status				
Married	267 (89.3)	212 (79.4)	1	
Divorced	20 (6.7)	7 (35.0)	0.14 (0.053-0.37)	<0.001
Other (includes single and widowed women)	12 (4.0)	10 (83.3)	1.30 (0.28-6.09)	0.74
Husband Income				
Earns income	245 (91.8)	196 (80.00)	1	
No income earned	22 (8.2)	16 (72.7)	0.67 (0.25-1.79)	0.42
Financial support				
No support	50 (16.7)	32 (64.0)	1	
Has support	249 (83.3)	197 (79.1)	2.13 (1.11-4.10)	0.02
Number of children				
1	99 (33.1)	79 (79.8)	1#	
2	91 (30.4)	70 (76.9)	0.84 (0.42-1.69)	0.63
3	60 (20.1)	43 (71.7)	0.64 (0.30-1.35)	0.24
4	31 (10.4)	23 (74.1)	0.73 (0.28-1.87)	0.51
5+	18 (6.0)	14 (77.8)	0.89 (0.26-2.99)	0.84
Whether any children died				
Yes	269 (8.7)	23 (88.5)	2.49 (0.73-8.57)	0.15
No	273 (91.3)	206 (75.5)	1	
History of miscarriage				
Yes	39 (13.1)	34 (87.2)	1	
No	259 (86.9)	194 (74.9)	0.44 (0.16-1.17)	0.1
Stage at which pregnancy was discovered				
First month	116 (38.8)	94 (81.0)	1	
2 <sup>nd</sup> month	88 (29.4)	65 (73.9)	0.66 (0.34-1.29)	0.22
3 <sup>rd</sup> month	59 (19.7)	43 (72.9)	0.63 (0.30-1.32)	0.22
After 3 <sup>rd</sup> month	36 (12.0)	27 (75.0)	0.70 (0.29-1.70)	0.43
Whether pregnancy was planned				
No	145 (48.5)	101 (69.7)	1	
Yes	154 (51.5)	128 (83.1)	2.14 (1.24-3.72)	0.007

Characteristics	N (%)	N (%) Registered for ANC	Odds ratio (95% CI)	p
Feelings about pregnancy				
Happy	184 (61.5)	151 (82.1)	1	
Neither happy/troubled	11 (3.7)	8 (72.7)	0.58 (0.15-2.31)	0.44
Troubled	104 (34.8)	70 (67.3)	0.45 (0.26-0.78)	0.005

# Score test for trend  $p=0.42$

Although there appeared to be an increasing trend of ANC registration with age, it was not statistically significant, with a score test for trend  $p=0.26$ . There was no evidence of an effect of age on ANC registration when age was used as a continuous variable in logistic regression.

There was no difference in ANC registration between apostolic and non-apostolic women. Women who lived in rented accommodation and those who lived with family as dependents were more likely to register for ANC than those who owned the accommodation.

### 6.3.1 Variables selected for multivariable analysis and justifications

#### Selection of the socioeconomic variable to use in the model

Only one socioeconomic variable could be included in the model to avoid collinearity. The following results were used in deciding which would be the best variable to be included in the model: There was no evidence of association of ANC registration with whether a woman earned an income (and also with monthly income earned by participant), therefore neither of these variables were included in the model. There was an association of partner income with ANC registration, but the household income was deemed more appropriate because it captured the total financial resource that was potentially available to the participant. The food security variable was deemed to be on the causal pathway from household income to ANC registration as it is a direct result of how much money there is in the household, so it was eliminated from the model. The variable for whether the woman had financial support from someone was eliminated from the model because it was also deemed to be on the causal pathway for household income. The other three variables (tenancy, type of toilet used, and source of water) were eliminated from the model because they were considered proxies for socio-economic status, and could also be perceived as directly influenced by household income.

After these considerations, the household income variable was considered the appropriate socioeconomic variable to include in the model. A decision had to be made on whether to use it as a continuous variable (which assumes a linear relationship between the explanatory variable and the dependant variable) or as a grouped categorical variable. The likelihood ratio test for departure from linearity favoured a linear relationship,  $p=0.41$ , hence it was decided to use the household income variable as a continuous variable in order not to lose data through grouping. The variable was divided by ten in order to give odds ratios for a unit increase of household income of US\$10, which is easier to conceptualise than a unit increase of a single dollar.

### **Consideration of the history of miscarriage variable**

In univariable analysis this variable was weakly associated with ANC registration,  $p=0.10$ ; possibly because women who have had previous miscarriages might be more conscious of the need for health care during pregnancy. It therefore needed further investigation to see if it should be included in the model. The likelihood ratio test revealed that there was no evidence of an interaction between whether pregnancy was planned and history of miscarriage,  $p=0.14$ . Also, addition of the miscarriage variable into the model without the interaction term was not supported by the LR test,  $p=0.17$ . Thus this variable was eliminated from the model.

### **Final factors used in multivariable logistic regression model**

After careful consideration of factors as stated above and in the methods section, (section 4.5.2.1), the following factors were included in the final logistic regression model of factors associated with ANC registration: education (whether the woman reached ordinary level education), whether pregnancy was planned, household income and marital status. There was an interaction between education and whether pregnancy was planned, likelihood ratio test  $p=0.008$ ; women who attained ordinary level education and had planned their pregnancy were more than four times more likely to register for ANC than women who attained ordinary level education but had not planned their pregnancies (likewise when comparing women who attained ordinary level education and planned their pregnancies with women who planned their pregnancy but did not reach ordinary level).

There were no interactions noted between the following variables:

1. Marital status and whether pregnancy was planned, LR test  $p=0.5$
2. Marital status and household income, LR test  $p=0.59$

Household income and marital status remained associated with ANC registration, see table 6.4 for multivariable analysis results.

**Table 6.4: Multivariable analysis of factors associated with ANC registration**

Factor	Adjusted odds ratio (95% CI)	p value
<b>Ordinary level Education</b>		
Did not reach ordinary level	1	
Reached ordinary level, did not plan pregnancy	0.75 (0.32-1.77)	0.51
Reached ordinary level, planned pregnancy	4.24 (1.70-10.55)	0.002
<b>Whether pregnancy was planned</b>		
Did not plan pregnancy	1	
Planned pregnancy, did not reach ordinary level	0.58 (0.21-1.58)	0.28
Planned pregnancy, reached ordinary level education	3.27 (1.55-6.70)	0.002
<b>Household income</b>	1.02 (1.0-1.04)*	0.07
<b>Marital Status</b>		
Married	1	
Divorced	0.20 (0.07-0.58)	0.003
Other (includes single and widowed women)	2.40 (0.48-11.98)	0.29

\* Odds ratio for a \$10 increase in household income

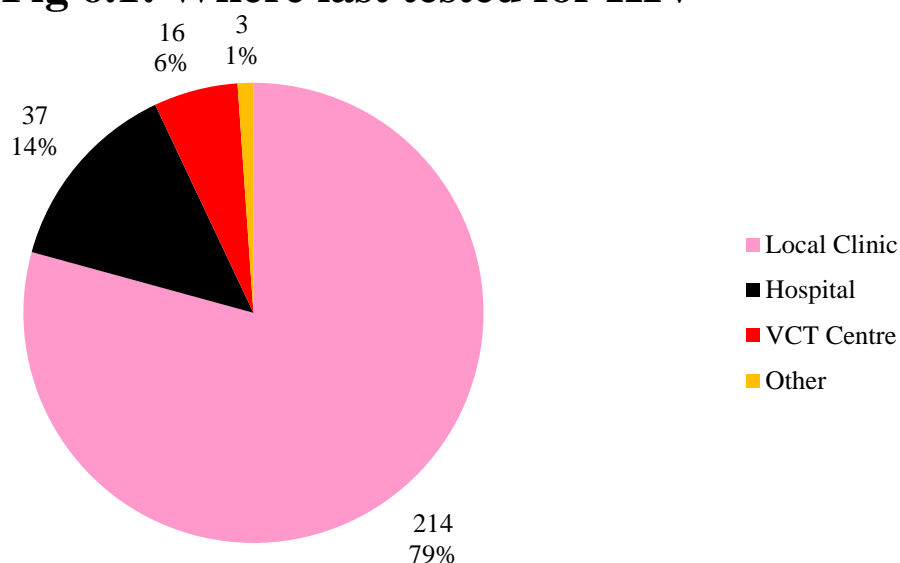
Of 70 women who did not seek ANC, only 6 reported visiting a health care centre to seek medical care (because they were not feeling well) during their pregnancy.

## 6.4 KNOWLEDGE OF HIV STATUS DURING PREGNANCY

### 6.4.1 Data on women who had ever been tested for HIV

272 (91.0%) of women had ever been tested for HIV. Most had last been tested at a local clinic (Fig 6.1).

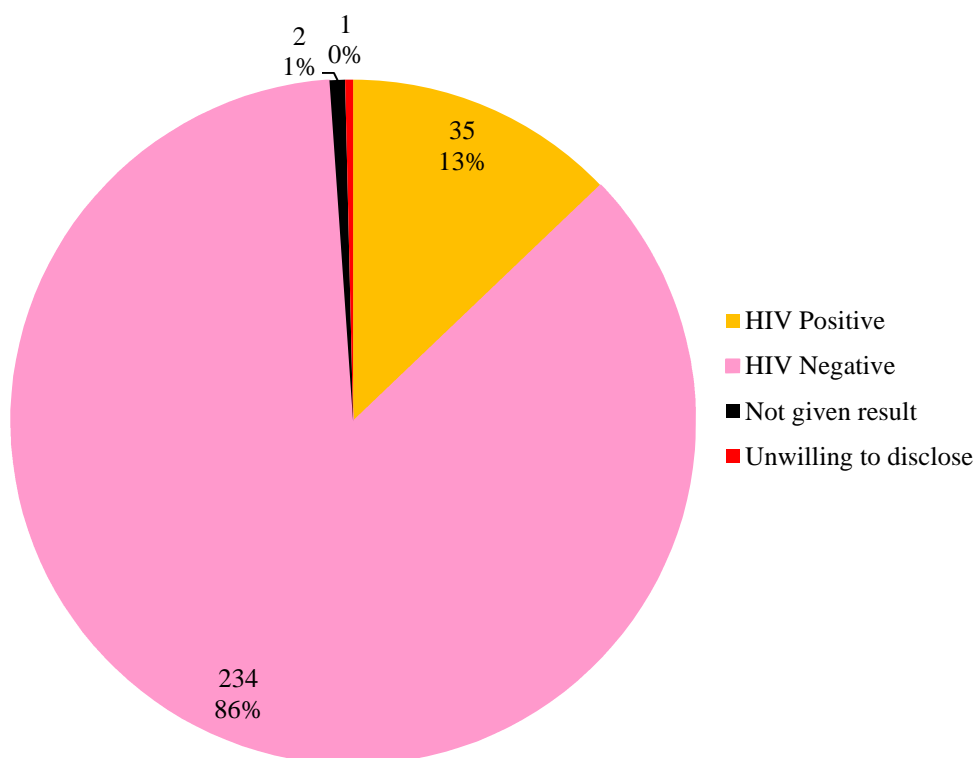


**Fig 6.1: Where last tested for HIV**

86.3% of those who had registered for ANC were last tested at a local clinic, compared to 41.9% of those who had not sought ANC.

#### HIV Results

35 (12.9%) of participants were HIV positive, and 86.0% were HIV negative (fig 6.2).

**Fig 6.2: HIV Status of Participants**

According to Ministry of Health guidelines at the time of the study<sup>139</sup>, pregnant women who tested HIV positive during pregnancy were to be started on twice daily zidovudine prophylaxis from 28 weeks of pregnancy, unless they were already on ART. At onset of labour, they were to take single dose nevirapine, stop zidovudine prophylaxis and take twice daily combivir (zidovudine +lamivudine) until one week after delivery. Women who were eligible for ART according to WHO clinical staging were to be referred to the ART clinic for initiation of ART. Those who were already on ART were supposed to continue on the regimen they had been prescribed.

7 (20%) of the HIV positive women reported that they were already on antiretroviral therapy (ART) which had mostly been initiated before they got pregnant; this was confirmed by examination of their hand-held maternity medical records which had this information. All reported that they took their ART drugs at all times as prescribed.

Of 28 women who were supposed to be started on ARV prophylaxis with twice daily zidovudine in line with Zimbabwe Ministry of Health guidelines, 19 (67.9%) received it. There was strong evidence of association ( $p=0.008$ ) between having registered for ANC and having taken Zidovudine prophylaxis: none of the women who failed to register for ANC had taken zidovudine, compared to 76.0% of those who had. No data were collected on the reasons why 24% of ANC-registered women did not receive zidovudine.

14 (73.7%) of the 19 participants who were given zidovudine prophylaxis reported that they took it every time as prescribed. Of the five women who reported adherence challenges, two reported that they sometimes forgot, one reported that she gave birth to her baby the day after she was prescribed the drugs, while one said she often travelled away from home, which made it difficult to take the zidovudine.

23 (82.1%) of the 28 women who were supposed to be given single dose nevirapine to take during labour received it. This was also strongly associated ( $p<0.001$ ) with having been registered for ANC (none of three women who failed to register had received it, compared to 23 of 25 (92%) of those who had registered). When asked why they did not receive single dose nevirapine to take during labour, three women said it was because they had not registered for ANC, one said the drug had been out of stock at the clinic, and one said she had initially tested HIV negative at the time she registered.

All 23 women who were given single dose nevirapine reported that they took it as directed.

### ARV prophylaxis for babies born to HIV positive women

According to Ministry of Health and Child Welfare guidelines at the time of the survey<sup>139</sup>, a baby born to an HIV infected mother was to be given single dose nevirapine and zidovudine for either 7 or 28 days depending on whether (and for how long) the mother had been on ARV prophylaxis. If the mother was already taking ART, the baby was not to be given single dose nevirapine, but zidovudine prophylaxis for either 7 or 28 days (7 days if the mother had been on ART for less than 28 days and 28 days if they had taken it for longer than this period). Using these guidelines, of the 35 babies born to HIV positive mothers, 12 were eligible for single dose nevirapine plus zidovudine for 7 days. Of these 12, eight were prescribed both drugs as appropriate, three were prescribed only zidovudine, and one got single dose nevirapine only. Sixteen were eligible for single dose nevirapine plus zidovudine for 28 days. Of these 16, eight (50%) were prescribed both drugs as appropriate, four were not prescribed any ARV prophylaxis (all four mothers had not received zidovudine prophylaxis during pregnancy), three were prescribed only zidovudine for 28 days, and one got single dose nevirapine at birth and zidovudine was only initiated at day 14. Seven infants were eligible for zidovudine alone. Of these seven, five were prescribed the zidovudine as appropriate, one got both single dose nevirapine and zidovudine while one received single dose nevirapine only. Participants who had not been prescribed the appropriate regimens were referred to the clinic nurses for prescription of the appropriate medicines.

27 (90%) of 30 babies (one missing value for this question; 31 babies were given ARV prophylaxis) who were started on ARV prophylaxis received it within 24 hours of birth.

### Disclosure of HIV positive status

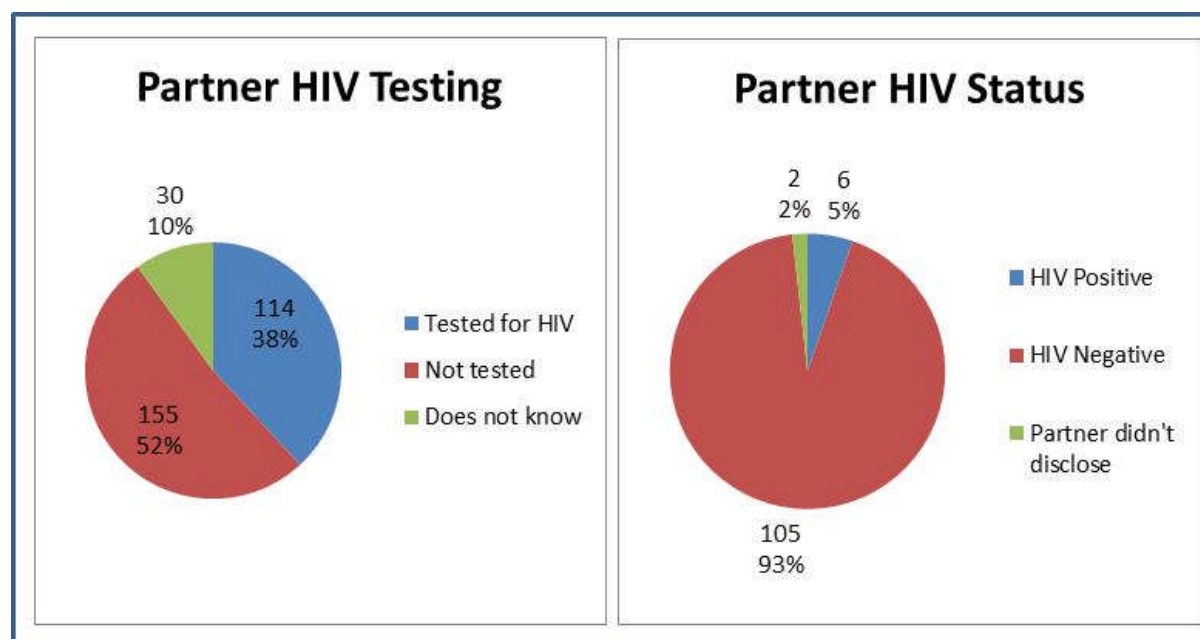
30 (85.0%) of women who had tested HIV positive reported that they had disclosed this status to someone. The majority (25) of these participants told their husband or sexual partner; ten told a friend and nine told their mothers.

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### **6.4.2 HIV testing of partners**

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38% of all participants reported that their partner had been tested for HIV, (fig 6.3).

**Fig 6.3: HIV testing of partners**

Of 11 HIV positive women who reported that their partners had been tested for HIV, six reported that their partners were also HIV positive, 4 reported that their partners were HIV negative, and one did not know her partner's HIV status. None of the 102 HIV negative women (who reported partner testing) reported that their partner was HIV positive.

#### 6.4.3 Knowledge of HIV Status during Pregnancy

The number of participants who knew their HIV status during pregnancy was obtained by adding the number of women who tested for HIV during their most recent pregnancy to those who had tested HIV positive prior to their most recent pregnancy.

272 (91.0%) women had ever been tested for HIV. However, only 241 (80.6%) of participants knew their HIV status when they were pregnant. There was a very strong association of knowledge of HIV status during pregnancy and having registered for ANC: 21.2% of women who failed to register for ANC knew their HIV status during pregnancy, compared to 98.7% among those who had registered,  $p < 0.001$ . Table 6.5 shows results of the univariable analysis of factors associated with knowledge of HIV status during pregnancy. As expected, many of the factors which were found to be associated with ANC registration were also associated knowledge of HIV status.

**Table 6.5: Univariable analysis of factors associated with knowledge of HIV status during pregnancy**

Characteristics		N (%)	N (%) Knew HIV status in pregnancy	Odds ratio (95% CI)	p
Registration for ANC					
	Yes	229 (76.6)	226 (98.7)	276.22 (77.27-987.40)	<0.001
	No	70 (23.4)	15 (21.4)	1	
Age (years)	15-24	141 (47.8)	111 (78.7)	1	0.88
	25-30	86 (29.1)	67 (77.9)	0.95 (0.50-1.83)	
	30+	68 (23.0)	59 (86.8)	1.77 (0.79-3.98)	
Religion					
	Non-apostolic	215 (71.9)	215 (71.9)	1	0.29
	Apostolic	84 (28.1)	84 (28.1)	1.45 (0.74-2.84)	
Education					
	Did not reach O Level	79 (26.4)	58 (73.4)	1	0.062
	Reached O Level	220 (73.6)	183 (83.2)	1.79 (0.97-3.30)	
Food security					
	No food problems	217 (73.1)	178 (82.0)	1	0.27
	Food problems	80 (26.9)	61 (76.2)	0.70 (0.38-1.31)	
Income					
	Earns an income	90 (30.2)	70 (77.8)	1.28 (0.70-2.35)	0.43
	No income	208 (69.8)	170 (81.7)	1	
Marital Status					
	Married	267 (89.3)	221 (82.8)	1	<0.001
	Divorced	20 (6.7)	9 (45.0)	0.17 (0.67-0.43)	
	Other (includes widowed and single women)	12 (4.0)	11 (91.7)	2.29 (0.28-18.17)	
Husband Income					
	Earns income	245 (91.8)	203 (82.9)	1	0.9
	No income earned	22 (8.2)	18 (81.8)	0.93 (0.30-2.89)	
Financial support					
	No support	50 (16.7)	35 (70.0)	1	0.04
	Has support	249 (83.3)	206 (82.7)	2.05 (1.03-4.09)	
Number of children	1	99 (33.1)	79 (79.80)	1#	0.39
	2	91 (30.4)	77 (84.6)	1.39 (0.66-2.95)	
	3	60 (20.1)	48 (80.0)	1.01 (0.45-2.25)	
	4	31 (10.4)	24 (77.4)	0.88 (0.33-2.30)	
	5+	18 (6.0)	13 (72.2)	0.66 (0.21-2.06)	
Whether any children					
Died	Yes	26 (8.7)	22 (84.1)	1.36 (0.45-4.10)	0.59
	No	273 (91.3)	219 (80.2)	1	
Previous miscarriage					
	Yes	39 (13.1)	35 (89.7)	1	0.13
	No	259 (86.9)	205 (89.1)	0.43 (0.15-1.27)	

Characteristics	N (%)	N (%) Knew HIV status in pregnancy	Odds ratio (95% CI)	p
<b>Whether pregnancy was planned</b>				
No	145 (48.5)	107 (73.8)	1	
Yes	154 (51.5)	134 (87.0)	2.38 (1.31-4.33)	0.005

# Score test for trend p=0.46

When thinking about factors to include in the model for multivariable analysis of factors associated with knowledge of HIV status during pregnancy, ANC registration was considered as the main determinant of knowledge of HIV status. However, because it was deemed to be on the causal pathway for all the factors which were deemed associated with knowledge of HIV status during pregnancy, it was not included in the final model. The factors included in the final model were: education, whether pregnancy was planned, household income, and marital status. Only education, whether pregnancy was planned and marital status remained associated with knowledge of HIV status during pregnancy (Table 6). There was an interaction between education and whether pregnancy was planned, LR test p=0.006

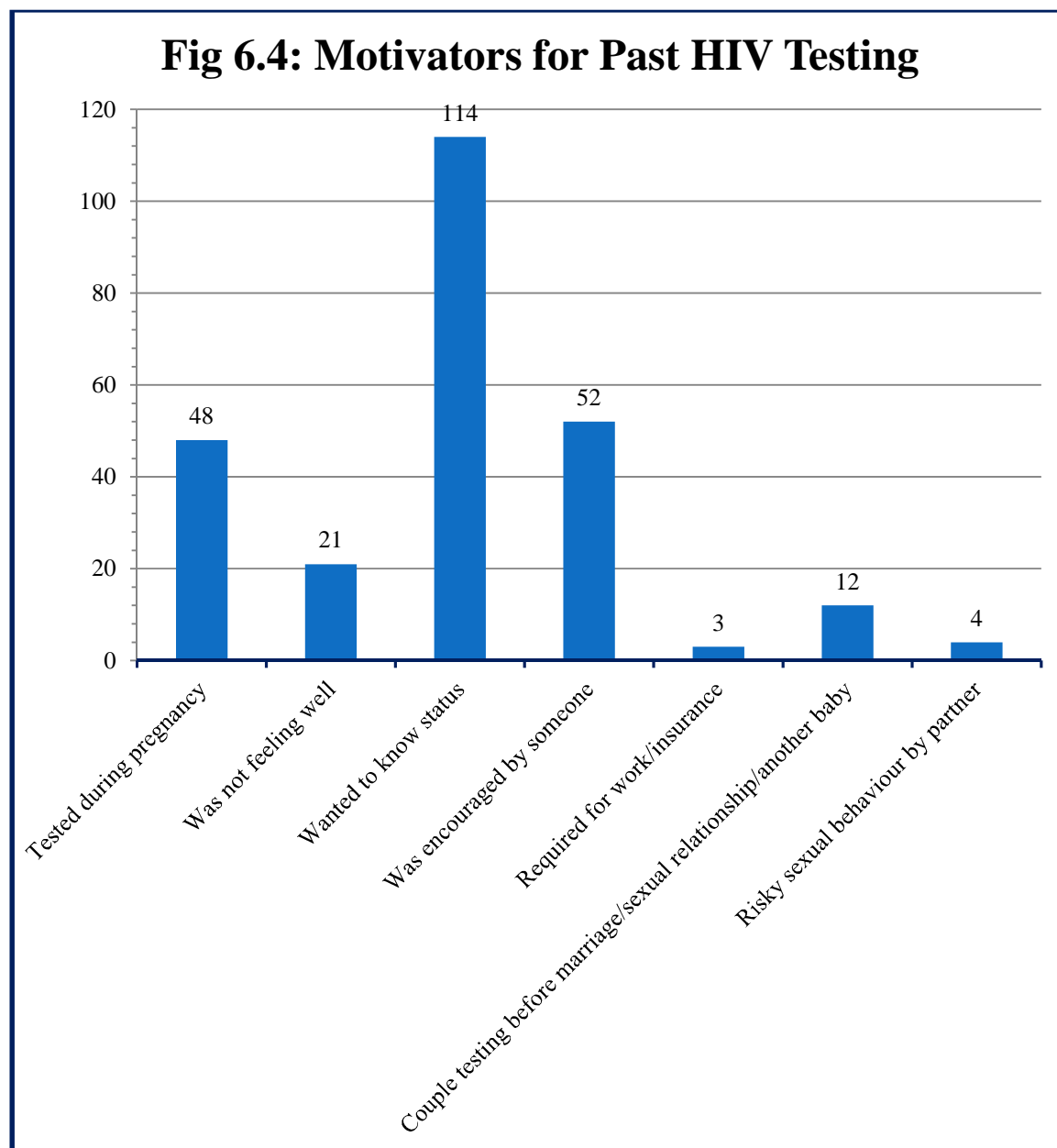
**Table 6.6: Multivariable analysis of factors associated with knowledge of HIV status during pregnancy**

Factor	Adjusted odds ratio (95% CI)	p value
<b>Ordinary level Education</b>		
Did not reach ordinary level	1	
Reached ordinary level, did not plan pregnancy	0.57 (0.23-1.44)	0.23
Reached ordinary level, planned pregnancy	6.72 (2.43-18.53)	<0.001
<b>Whether pregnancy was planned</b>		
Did not plan pregnancy	1	
Planned pregnancy, did not reach ordinary level	0.42 (0.15-1.23)	0.11
Planned pregnancy, reached ordinary level education	4.99 (2.11-11.81)	<0.001
<b>Household income</b>	1.01 (0.99-1.03)*	0.45
<b>Marital Status</b>		
Married	1	
Divorced	0.22 (0.08-0.62)	0.004
Other (includes single and widowed women)	3.99 (0.48-33.25)	0.20

\*Odds ratio for a \$10 increase in household income

#### 6.4.4 HIV Testing Behaviour before Pregnancy

Of women who had ever been tested, 150 (55.1%) of women had tested prior to the last pregnancy. 84 (55.6%) had been tested once before, and a quarter had been tested twice before. The most common reason for testing was the desire to know HIV status, fig 6.4.



The time that had elapsed since last test for women who tested during pregnancy and those who did not test is given in Table 6.7.

**Table 6.7: Time since last HIV tested**

a) Number of <i>months</i> since tested for those tested during pregnancy	N (%)	b) Number of <i>YEARS</i> since tested for those NOT tested during pregnancy	N (%)
1-3	6 (4.9)	1 year	8 (29.6)
4-6	11 (9.0)	1-2 years	10 (37.0)
7-9	13 (10.7)	3 years	3 (11.1)
10-12	37 (30.3)	4 years	1 (3.7)
13-18	8 (6.6)	5 years	5 (18.5)
19-24	15 (12.3)		
25-36	19 (15.6)		
>36	13 (10.7)		

10 of 127 (7.3%) women reported that they had previously been tested HIV positive. Three of these women did not seek ANC. Two of them had known their HIV status for about a year, and one had known for about two years. All three reported that they had not sought ANC because they had had no money for the registration fees.

10 women had seroconverted since their last HIV test. The median number of years since the last HIV test was 3.5 years.

#### 6.4.5 Referral for HIV-related care

13 (37.1%) of 35 HIV positive women reported that they had not been referred for HIV-related health care by clinic staff i.e. they did not know what next to do regarding their own or their baby's HIV health care. Three of these women were still in the postnatal ward at the time of interview, but the other ten had already been discharged and they did not know where to go next for HIV-related care.

Four of the 22 women who had been referred for care did not know when they were supposed to seek that care. Eleven women had already sought HIV related care, including seven of those who had tested HIV positive before pregnancy.



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**6.4.6 Participants' perception of risk of mother to child transmission of HIV**

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18 of the 35 HIV positive women believed that their baby was at risk of acquiring HIV. 13 reported that they thought their baby was not at risk, and four said they did not know. The participants who said the baby was not at risk believed that the ARV prophylaxis they had received (or that given to the baby), rendered them protected from HIV. 31 of 35 women reported that they had been educated on how they could reduce the chances of transmitting HIV to their babies.

It emerged during the interviews that some HIV positive women who had not registered for ANC, and thus had not been tested for HIV at the clinic chose not to tell the nurses about their HIV status. They did not therefore receive the appropriate ARV prophylaxis at time of delivery. Such women were referred back to the nurses after the interview for institution of the appropriate care.

**Intention to attend the six weeks visit**

Almost all participants (99.3%), regardless of HIV status reported that they intended to attend the six-week postnatal visit.

## 6.5 SHORT DISCUSSION OF FINDINGS

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This chapter gives a quantitative estimate of the magnitude of the problem of entry into the PMTCT continuum of care. For a woman to receive the appropriate PMTCT interventions, her HIV status must be known. Similarly, for a baby to be started on cotrimoxazole prophylaxis at age six weeks, he or she must be identified as HIV exposed. In the setting at Mbare Clinic (and indeed in many other settings), ANC registration is the main determinant of knowledge of HIV status during pregnancy (and of HIV exposure status for the baby). This chapter provides data on the uptake of ANC registration and the factors that are associated with it. Awareness of these factors will help in the formulation of targeted interventions for increasing the uptake of ANC registration and associated knowledge of HIV status during pregnancy.

This cross-sectional survey revealed that almost a quarter of women did not register for ANC. Those who registered did so very late, at an average of 29.5 weeks gestation. Most (85%) participants who did not register reported that it was because they could not afford the ANC fees. That user fees were a barrier is supported by the fact that there was a 2% increase in odds of ANC registration with each \$10 increase in household income. It therefore follows that poverty-alleviation programs may have a significant impact on the rates of ANC registration in this community. As expected, ANC registration was found to be highly associated with knowledge of HIV status during pregnancy.

Because ANC registration is a critical step in the PMTCT cascade, it is clearly important to explore the barriers to ANC registration further. In the next chapter, a more nuanced understanding of the barriers to ANC registration is presented, where results of a qualitative study that was conducted among women who did not register for ANC and those who registered late are presented.

An important finding of this study is the interaction of education and planned pregnancy in bringing about higher levels of ANC registration. This means that the importance of education of the girl child cannot be over-emphasized. An educated woman is better able to plan her pregnancy and all associated events. It is important to put in place measures to discourage unplanned pregnancies, as they are less likely to be registered. In this study, about half of the pregnancies were reported to have been unplanned. Prevention of unplanned pregnancies has already been identified by WHO as the second of four prongs of the strategy

for elimination of mother to child transmission of HIV. Key in achieving this objective is the elimination of unmet need for family planning.

The results presented in this chapter will be discussed more fully and in the light of other findings in the Discussion Chapter.

## **CHAPTER 7: QUALITATIVE FINDINGS ON BARRIERS TO ANC REGISTRATION**

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### **7.1 OVERVIEW**

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In this chapter I describe results of the qualitative study undertaken to explore reasons for failure to register for ANC. The study was conducted among women in Mbare who had just delivered babies. Women were eligible for participation in this qualitative study if they 1) had recently delivered a baby, 2) were residing in Mbare as evidenced by the address given on the participant's medical record, and 3) had registered for ANC later than 24 weeks of pregnancy or had not sought ANC at all. Written informed consent was obtained from all women before participation. The first 21 eligible participants were invited for in-depth interview. The number of 21 was based on pragmatic considerations and on the belief that with 21 participants it was highly likely that theoretical saturation would be reached. Interviews were conducted by the candidate in Shona (the local language in Zimbabwe), in private, in a closed room at Mbare Clinic. The interviews were digitally recorded, transcribed, translated into English and analysed according to thematic analysis.

### **7.2 DESCRIPTION OF MATERNITY SERVICES AT MBARE CLINIC**

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As described in Chapter 5, Mbare Clinic is a large polyclinic that is divided into the outpatients department, family health services clinic and maternity clinic. An average of 400 babies are delivered in the maternity clinic in a month. The ANC clinic is housed within the maternity clinic. It is open four days a week on Mondays, Wednesdays, Thursdays and Fridays. On three of the days the clinic sees about 70 clients a day, half of which are existing/repeat ANC visit clients and the other half are bookings and new registrations. Only repeat ANC visit clients are seen on Wednesdays (also about 70 women).

The ANC clinic operates under guidelines of City of Harare, which are based on the national guidelines from the Ministry of Health and Child Welfare which at that time required that women seek ANC before 16 weeks gestation. The clinic has posted fliers throughout the clinic buildings to encourage women to register their pregnancies from three months gestation. Women are asked to pay US\$30 for ANC booking fees (previously this amount was \$50, and was reviewed downwards a few months after this study began, in December 2009). The fees cover all examinations and tests done during pregnancy, delivery, and all

postnatal care up to six weeks post-delivery. To discourage late registration Harare City Health Department has fixed the fees at \$30 regardless of time of registration. Thus women who did not seek any ANC but come to the clinic for delivery are still expected to pay the fees in full. To ensure recovery of fees owed, the clinic detains women in the clinic after delivery until they have paid the required \$30.

The clinic operates an appointment system for ANC registration where a woman must first come to the clinic to make an appointment for the day of registration. On the appointed date women start by paying the fees. Women then take part in a group education session with all the other mothers who registered for ANC on that day (usually 35-40 women). The education session is given by a midwife and covers what to expect during ANC, any clinic procedures that may be conducted, and how to take good care of themselves during pregnancy. Women are also given a tour of the clinic and given instructions on what to do and where to go when they are in labour. Each woman undergoes a physical examination and has blood drawn for various tests including HIV.

The maternity clinic is open 24 hours a day and is staffed by qualified registered nurse midwives. Should there be complications that cannot be managed at the clinic, women are referred to Harare Central Hospital, one of the two largest central hospitals in the country which is about 10 minutes ride by ambulance/taxi.

### **7.3 RESULTS OF THE QUALITATIVE STUDY**

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Twenty one participants with a median age of 26 years (age range 16-38 years) were interviewed in-depth. All participants who were asked to participate in this study agreed to participate. Six were HIV positive, one did not know her HIV status and the rest were HIV negative. The majority (17) were married. Only seven of the 21 women earned their own incomes. 16 women had registered late for ANC, mostly at eight months, with some registering as late as one week before delivery. Four women did not seek ANC at all. All registered women delivered at a health care facility (Mbare Clinic or Harare Hospital). Of the four unregistered women, two delivered at a health care facility and two delivered at home.

There were six principle reasons that were cited as barriers to ANC registration, including user fees, fear of HIV testing, nurses' discourteousness, unsupportive male partners, long waiting queues at the clinic and unplanned pregnancy.

Before presenting findings from the participants' narratives two case studies will be presented in order to give a wider picture of the context of the women's lives.

### Box 7.1: Fari's Case Study

Fari was 24 years old. She was married with three children, including the baby. She was self-employed as a meat vendor. Her husband was not employed. She registered for ANC when she was eight months pregnant with the recently delivered baby, and was at that time diagnosed HIV positive.

Fari's previous HIV test was done three years ago, when she was pregnant, and she was HIV negative at that time. She reported that she delayed seeking ANC because she did not have money. She and her husband struggled to make ends meet: she did not make much money from her vending business and her husband was finding it difficult to get a job. She said she had to meet all the household expenses which made it difficult to save up for ANC registration, but she would put aside a small amount whenever she could. During her pregnancy (before she registered), she was often unwell. She longed to seek health care for her illness but she worried that if she went to the clinic she would use up all the money that she was saving up for ANC registration. As a result she did not seek any health care for her illness until she was eight months pregnant (when she finally registered for ANC). Fari reported that during her pregnancy she was often worried about her health and the health of the baby. She needed to know whether her baby was alright. She knew a woman who did not seek ANC whose baby had died in the womb and she had not known.

*Another woman we lived with...her baby died in the womb and she had not registered.... So those are things which kept bothering me. What if it happened to me when I was not registered; how would I know that this is what had happened?*

Fari disclosed her HIV status only to her husband. She reported that she could not disclose to anyone else because she did not trust other people to uphold confidentiality. She reported that her community was one that did not accept HIV positive people. She felt that if people knew her HIV status they would not buy her meat, and her relatives would not want to eat the food she had prepared. Because of this she was determined to keep her HIV status a secret. She lived with her sister in the same one-roomed residence that she and husband and children shared, but she did not disclose her status to her.

*You first have to examine your family to see if there are no people who gossip, okay. You may say a-a let me tell my younger sister but then at the end of the day everyone knows about your HIV status.*

At the time of interview (when the baby was two weeks old), Fari had not yet sought any HIV care for herself; she had not had a CD4 count and had not been told anything about how she should seek care for her HIV infection. Her baby was taking nevirapine prophylaxis and she was aware that the baby would be started on cotrimoxazole prophylaxis at six weeks. She was hoping that at that time (at the six weeks visit) the nurses would also prescribe something for her HIV care.

### Box 7.2: Mutsa's Case Study

Mutsa was 19 years old. She was married with one baby and lived in Mbare with her husband together with her in-laws (at the in-laws' residence). She was not employed. She registered for ANC at seven months of pregnancy. She was tested for HIV when she was pregnant, and she tested HIV negative.

She reported that she delayed registering because her husband would refuse to give her the money for registration. He had the money, but would not give it to her. She tried to convince him to but he kept refusing because he did not appreciate the importance of ANC, and kept saying he would give the money to her at a later date, towards delivery.

*“...men do not really know the purpose of ANC registration. They just think that one registers so that she will give birth at the clinic. Because I kept telling my husband on a daily basis; he actually drank beer yet I was telling him that I needed money for registration. And he would say, “Why do you want to register the pregnancy when it’s still this small? You will register later isn’t it there is still plenty of time until you are nine months pregnant?”*”

When Mutsa was pregnant she visited her aunt who lived in another town. The aunt gave her \$50 at the end of her visit. She took \$30 out of that money and registered herself for ANC. Her mother-in-law seemed to have been very supportive of her, and seemed to be aware of the irresponsible nature of her son. She told Mutsa not to reveal to her husband that she was already registered, and to keep requesting the registration money so that she would use it for something else when she was eventually given. To help keep Mutsa’s registration status from her son, Mutsa’s mother in law offered to hide the ANC registration records in her bedroom. Mutsa’s husband eventually gave her the registration money a few weeks before she was due to deliver.

Mutsa reported that she felt helpless when her husband refused to give her money for registration, she felt there was nothing she could do because he refused with his money. She longed for some financial independence, and wished she could get some capital that would put her into a buying and selling business. That way she would be able to spend the money however way she felt appropriate.

*“If only there were things that one could do, for example if you can get some capital then you can start selling your things, then you will know that I have got my own money that I can use for whatever I want to do... There will be no need for you to wait for someone to give you money. Like in my situation, my husband had the money. But you can’t snatch it away or forcibly take the money from him because it is his money.”*

During the interview, Mutsa also reported that nurses at the clinic do not treat women courteously. She said this was something that was widely discussed in the community, and also in her family. Her sister had tried to discourage her from registering at Mbare Clinic, telling her to go to a private clinic where patients were treated better. But she could not afford the private clinic, and had registered at Mbare Clinic hoping that the bad reports she had heard about the clinic were not true. Mutsa reported feeling very disappointed to have people’s reports confirmed: she reported that she herself was not treated well. She had an unassisted delivery while the nurses were sitting in the same room. (*Quote on this is in the main text*).

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### 7.3.1 User fees are a barrier to ANC registration

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#### **Poverty**

In this study, the main finding reported by women was that user fees are an insurmountable barrier to ANC registration. All interviewed participants reported that it was difficult to raise the ANC registration fees. Discussion with most participants revealed that they were very poor and were struggling to make ends meet; the majority talked about the tiny incomes that they or their partners earned and how it was nearly impossible to save up any money towards ANC registration.

*On a particular day my husband can bring home a meagre income of three dollars, on another day maybe he brings a mere five dollars, yet on another day he brings a*

*paltry dollar. So it is quite a challenge to save up a substantial amount of money. 24-year old HIV positive mother of three*

Many participants reported that they had attempted to bring a partial fee to the clinic in the hope that they could reach an agreement where they could pay the balance in instalments but were disappointed that the clinic only accepts full payment before ANC registration.

*800-311-3: I couldn't go to the clinic with a partial fee because they would not accept it. As you know if you just keep money in the house, nowadays it is a problem. You may encounter a problem and then you use that money.*

As a solution, the majority of participants wanted the authorities to reduce the fees to amounts that they could afford or to remove them altogether. Participants believed that once ANC fees were removed there would be a huge increase in the number of people who register for ANC. Indeed, there was evidence from the interviews that when the fees had been reduced from \$50 to \$30 this had resulted in more women registering.

*With me it (the reason for late ANC registration) was failure to raise money because initially it was at fifty dollars, is it? When it was reduced...that's when I was given money, and I came to register when it had come down to thirty dollars.*

However, because this is a very poor community, \$30 was still considered a lot of money for the majority of women. Only one woman said the fee of \$30 was affordable. She was different from the other women as she had a regular job which paid her a much higher salary than the average income of the women seeking care at Mbare Clinic.

### **Managing priorities**

In this community where abject poverty is the norm, ANC registration competed with many basic household priorities. The dilemma caused by poverty was apparent in many interviews. Women sometimes had to choose between saving up for ANC registration and other, sometimes critical or potentially life-altering alternatives. For example, some women who became unwell during their pregnancy would further endanger themselves and their babies by declining to seek health care in order to protect the savings they had made towards the ANC registration fees. They argued that seeking health care for their illness meant that they would have to pay a consultation fee and possibly buy some drugs, which would deplete the savings they were making towards ANC registration. This is particularly sad because if they had



afforded to register all these health care costs would have been free. Unfortunately, it turned out to be particularly important for those women who became ill to have registered early or to have an earlier HIV test; two of these women turned out to be HIV positive when they eventually tested at eight months of pregnancy and at delivery respectively. The following text is the justification that one of them gave for not seeking health care for the illness she experienced during pregnancy:

*When you get here you are asked to pay five dollars for the card (consultation fee). After you have paid five dollars you will then buy medicines, okay. The total amount you pay can go up to ten or fifteen dollars. That fifteen dollars is a substantial amount of money; if you keep it diligently it can increase to thirty dollars. **24-year old HIV positive mother of 3 (was tested HIV positive when she registered for ANC at eight months of pregnancy).***

For some participants, however, ANC registration was further down the list of priorities; these women described more immediate expenses to be dealt with, for example food, rent and school fees for the children. Other priorities included the requirements for a new baby e.g. clothes, diapers and other new-born requirements, known locally as ‘preparation’.

*I had too many expenses in that the little boy...the first born child goes to school...you have to see to the food in the house, and he needs to go to school. So there are many expenses...that is why I registered at eight months.*

*We were facing difficulties to the extent that we even had problems getting food in the household...So the financial burden will be heavy; you need food, then the registration fees; then ‘preparation’. There will be too many expenses at the same time.*

### **Feelings about non-registration: Anxiety due to exclusion from the clinic**

For women, not having paid the required ANC registration fees meant exclusion from the health care system. Women reported feeling helpless and “distressed” by this exclusion. As stated above, a number of women stated that they had wanted to go to the ANC clinic because they had been ill during pregnancy. However they opted not to seek care because they could not afford the consultation fees and other costs associated with health seeking as

stated above, or the belief that the primary care clinic would not assist any woman who had not registered. As a result, for many women the period before seeking ANC was laced with anxiety with some women reporting worrying about their own health while others worried about the welfare of the baby they were carrying; specifically whether the baby was healthy and properly positioned in the womb. Other women reported worrying about their unknown HIV status and the possibility of passing on HIV to their baby in the event that they had HIV. It was clear that the majority of women appreciated the importance of ANC attendance and longed for the reassurance that would only come through ANC registration.

*It bothered me because the people in my family kept telling us to find some money (for ANC registration). They would say nowadays there is HIV. You might be infected with HIV, and the baby may contract the disease. But if you receive protection early, the baby may be born without HIV. 19-year old married mother of one, HIV negative*

*I worried most about the baby; that it could possibly be in a breach position and I wouldn't know about it. Or that the baby could die in the womb. 25 year-old married mother of one, HIV negative*

*Another woman we lived with...her baby died in the womb and she had not registered.... So those are things which kept bothering me. What if it happened to me when I was not registered; how would I know that this is what had happened? 24-year old HIV positive mother of 3 (was tested HIV positive when she registered for ANC at eight months of pregnancy).*

Although in general participants displayed a strong appreciation of the importance of ANC, there were a few exceptions: three women reported that they had not been bothered by their delay in ANC registration. One of these women reported that she was not worried because she and her husband had tested for HIV before she got pregnant, so she was not bothered because she already knew that she was HIV negative. The other two women reported that they had not been worried because they had felt they had had plenty of time before they delivered. These women showed a lack of understanding of the holistic importance of ANC, believing in one instance that early ANC registration was only important for HIV testing, and in the other instances it was important for assisted delivery at the end. The implications of these exceptions will be discussed in the next and later sections.

In addition to user fees, other important barriers to ANC emerged from the interviews; some of which were interwoven with user fees, as will be seen in the discussions to follow.

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### 7.3.2 Fear of HIV testing as a barrier to ANC registration

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#### *Fear of an HIV positive diagnosis*

One barrier to ANC registration that was frequently discussed in the interviews was the fear of HIV testing, although none of the interviewed women reported it as her own experience. Women suggested that it is difficult for some women in their community to test because they are afraid of discovering that they are infected with HIV. There was indication that the fear is driven by suspicion that they had been exposed to HIV, for example because of husband/partner infidelity.

*A-a, you know what happens in life; you can discover that your husband is having extra marital affairs. So you can find such a woman saying a-a, that woman who is having a relationship with my husband, does she not have the disease, and the like. So one would have been thinking that oh my god, I think I have the disease. But for me to think about it...for her to think about going for testing really she will be scared...what if I am found to be infected?* **24-year old HIV positive mother of 3 (was tested HIV positive when she registered for ANC at eight months of pregnancy).**

There was perception that knowledge of an HIV positive status could cause someone to “become stressed” as they worried about their health. Another potential source of mental unrest that was reported to deter HIV testing was the fear of stigma. There was recurrence of the idea that women worried about “how people would perceive them” if they discovered their HIV positive status. The community was viewed as one that has not accepted HIV positive people: there was fear that disclosure of an HIV positive status would result in ridicule:

*There were other people who had tested HIV positive whom people talked about saying, “hee-e this person has such an HIV status,” and they would laugh.* **33-year old widowed mother of five, tested HIV positive at eight months of pregnancy**

*There could be some talk that could affect you such that you would never have a peaceful mind, such things as ah! This is the HIV status of this person; this is how it happened, and the like. Do you know that if you have an argument or heated exchange with a relative it can degenerate into them saying “Ha-a (after all) you have such an HIV status”, and the like...maybe in the public with many people around. **24-year old HIV positive mother of 3 (was tested HIV positive when she registered for ANC at eight months of pregnancy).***

There was also fear of losing existing social relationships as people in the community were reported to be unwilling to associate with an HIV positive person. In particular women were said to be afraid of abandonment by partner/husband as narrated by this 24-year old HIV positive mother of three: *“Now how do you tell your husband that you have been found to have the disease? He may... like..., maybe he can say I am no longer interested in you, and he just leaves you.”*

Because of these fears women were reported to find it preferable to live in ignorance, with the belief that the emotional stress and pain that followed an HIV positive diagnosis could itself result in deterioration of one's physical health: *“Maybe you can end up being sick because of thoughts of, “A-a, what is everyone's perception of me?”*

### ***Perception of ANC Clinic as an HIV Testing Site***

Although overall, study participants were aware of the importance of ANC, the fact that fear of HIV testing was a barrier to ANC suggests that the ANC clinic is being perceived by some women as mainly an HIV testing clinic. The other benefits of enrolling for ANC are either ignored or are unknown, as typified by the participant who delayed seeking ANC because she already knew her HIV status.

Another important finding was the view among women that it was difficult to refuse testing. Although women understood that in theory they could refuse testing if they did not want to, they reported that the environment at the clinic did not make it easy to opt-out: registering women were told to go into the testing clinic all at once, and if someone was unwilling then they would remain sitting outside. Participants reported that women found it difficult to

remain outside while everyone else was going in because they feared that other women would assume that they had already been diagnosed HIV positive. This assumption could lead to unpleasant talk and potential stigma, and women were keen to avoid that by just going in for testing even if they really did not want to.

*A-a , what happens is when we are in a big group like that and it is called out, “It is now time for people to get tested,” ...so if you think you are...some are going and you are not going...the people wonder why you are not going. So in the end you will just say let me also go where the others are going...One will think that if she refuses everyone will wonder what she is afraid of; “Oh my god, maybe she is HIV positive.”*

**33-year old widowed mother of five, tested HIV positive at eight months of pregnancy**

Whilst it is encouraging in public health terms that the clinic manages to test the majority of registering women, the difficulty they perceive in opting-out of testing could make someone who is undecided about HIV testing avoid ANC altogether. Indeed, participants reported that they knew of many women who chose to only come to the clinic when they were in labour because they wanted to avoid HIV testing. This is obviously a draw-back to the provision of PMTCT services as the principal component of the services i.e. HIV testing, is the very thing that keeps some women away.

***Accounting for fear of HIV testing in the interviews***

None of the women who talked about HIV testing as a barrier to ANC reported it as their own experience. Rather, each woman who talked about it described it as the experience of other women in her community. The participants would then add that it was foolish not to test for HIV because then one would not get the appropriate PMTCT services that could benefit the baby. *“We could regard this as having a shallow mind because you could be harming your own and you could be killing yourself.”* Thus it is clear that even if the woman may have been describing her own experiences she would consciously distance herself from such actions, describing them as the actions of others in order not to be associated with the image of a “foolish” woman who risked the health of her baby by not testing for HIV early. In addition, there is some sort of shame associated with admitting that one is scared of HIV testing, as seen by the women’s inability to refuse testing if they did not want to. Thus it is possible that some women could have used the interview to deliberately create an identity of a responsible woman who is not scared of HIV testing.

Therefore this analysis suggests that there may be additional reasons that hinder early registration, such as fears around HIV testing, but that these may be considered more shameful to admit as they may transgress expectations of what is involved in being a responsible woman and mother. As a result not being able to afford the ANC fees may be perceived to be the more socially acceptable reason and therefore the one more readily proffered in the interview. Whilst this may still be the primary reason, the focus on registration fees may conceal additional reasons at play.

Another instance where some identity creation work could have occurred in the interviews was on the other commonly discussed barrier, the bad treatment of clients by nurses.

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### **7.3.3 Nurses' discourteousness as a barrier to ANC registration**

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As with the case of fear of HIV testing, none of the interviewed women reported that they had failed to register for ANC because they feared the nurses. However, seven interviewed women reported that they knew other women in the community who did not seek ANC because they wanted to avoid the clinic nurses, who were reported to be discourteous towards clients. They each went on to describe personal experiences of how badly they had been treated by the nurses. They used these examples as reinforcements of their view that women stayed away from the ANC clinic in order to avoid this bad treatment.

*Each time I had my blood pressure checked; they first checked my blood pressure okay? Then...the nurse was shouting at me saying, "You young people you rush to engage in sexual relations with men, this and that." 16 year old married mother of one*

This kind of accounting is similar to that of the fear of HIV testing in that none of the women gave this as the reason that they themselves had failed to register. They instead preferred to talk about the more 'respectable' reason (that they could not afford the ANC fees) which they could demonstrate was beyond their control. However, it is different from fear of HIV in that there is no shame associated with admitting to an unpleasant experience with a nurse, hence the readiness to describe their personal experiences (set out below).

#### ***Unequal treatment of clients at time of delivery***

There was feeling that there were 'good' and 'bad' patients; good patients/clients were treated well, and bad clients not so well. Three types of 'bad' patients were identified in the

interviews: 1) women who had not registered for ANC; 2) women who did not behave well at the clinic, e.g. those who made a lot of noise during labour or those who kept asking for clinical examinations despite nurses' advice against it, and 3) HIV positive women.

#### *Unregistered women*

Women who did not seek ANC or those who registered late were made to feel unwelcome at the clinic; they were treated as if they did not belong. As a result, a few women reported that they felt ANC registration was a way of guaranteeing good treatment by nurses at the time of delivery as indicated by this 22-year old woman's response when asked what she thought were the advantages of ANC registration: "*So that the nurses will serve you more nicely...without shouting at you because they know that 'A-a, really, this person registered, she is our patient who belongs here.'*" Both registered and unregistered participants expressed this view. Examples of differences in treatment included 1) discourteous communication; 2) if there were many women who had given birth, unregistered women were made to sleep on mattresses that were placed on the floor, even when there were vacant beds in the wards; 3) being made to wait while nurses were serving those who had registered.

*(If you have not registered) you are not even civilly treated, you will actually be made to sit on the benches and wait for a long time while they help those ones who would have registered...No one (i.e. no nurse) examined us. We were eventually examined by a man who works on the ambulance who eventually came.* **22 year-old mother of three who did not register for ANC**

*When I delivered I saw some who were made to sleep on the floor, in the maternity wards. They had not paid...They had not registered. I think if there is a shortage of beds some who have delivered will be told to sleep on the floor...But in that room I was admitted to there were some who were...there were no people on the beds...The beds were vacant but the women had delivered without having paid the fees.* **34-year old mother of three who registered when she was eight months pregnant**

The prospect of being treated differently makes unregistered women stay away from the clinic. What this therefore means is once the pregnant woman sees that she no longer fits the 'good patient' definition in terms of early registration, she might miss ANC altogether, and possibly not come for delivery as well (i.e. deliver at home) in order to avoid being treated badly by the nurses.

*HIV Positive Women*

HIV positive women were another group of patients who felt they were treated differently by the nurses. For example, this 33-year old mother of five reported that she felt the nurses had not wanted to perform clinical examinations on her because she was HIV positive:

*On the days I delivered the baby...Some women were examined more frequently, but you the (HIV) positive one maybe they will just look at you only once; or maybe they will say to you, “Haghh i-i, wait, your time is not yet up,” They would not check on your progression in labour. I thought they do a bit of discrimination in that area. 33-year old HIV positive woman*

One of the findings in the wider study is that some women who had not registered (and had therefore not been tested for HIV at the clinic) chose not to disclose the fact that they already knew they were HIV positive to the nurses. These interviews suggest that this may be due to fear of differential treatment. Unfortunately this increases the risk of HIV transmission to the baby as the mother does not receive the appropriate HIV prophylaxis to prevent transmission. Interviewed women reported that HIV positive women may choose not to disclose their status to the nurses because they are afraid of being mistreated, judged or ridiculed by them:

*A-a I think....I think in the person's mind they think that if I tell them (nurses), maybe they will laugh....maybe they will do some things. They will keep saying that this person is HIV positive, or maybe they will not treat you well. 33-year old HIV positive woman.*

*One may think that maybe the nurses will think that I am a promiscuous person. 24-year old mother of three, HIV positive*

*Women who 'misbehaved'*

Women believed that bad behaviour in the eyes of the nurses could result in punishment. The 'punishment' that was particularly dreaded was transfer to the central hospital, Harare Hospital (nicknamed Gomo). Some women reported that if the nurse did not like you, or was annoyed with you for some reason, she could get back at you by transferring you to the central hospital, 'claiming' that you had developed a complication that warranted referral. This was perceived as a punishment because the cost of transfer was very expensive: the woman would have to pay an ambulance fee of \$20, and at the hospital they would be asked



to pay about \$90 in hospital fees. This was of course too much money for many women. As a coping strategy, some women have resorted to not registering for ANC so that they could hold on to the \$30 registration fee. In the event that they are transferred to Harare Hospital they will use the money they have saved to contribute to the cost of the hospital fees. That way they will not have to pay both the clinic and the hospital.

*So now I kept going back there (to the examination room). That's what irritated them. Then they said to me...after they had examined me they said the foetus had deposited its excrement in the womb. But the foetus had not deposited its excrement in the womb...The people at the hospital actually asked me why I had been referred to them. And I said they told me that the baby had deposited its excrement in the womb. And they (the hospital people) said how come it's not written anywhere. When I delivered they noticed nothing wrong...they did not even see the baby's excrement in the womb.*

**Interviewer:** *Ok. So why do you think they sent you to Harare Hospital?* **Participant:** *Because I kept going back to the labour ward and telling them that I was about to give birth....Actually I went (to the hospital) together with another person. The other person I went with was screaming a lot when we were in the ward. They kept coming to the ward to tell her to keep quiet. They said to her, "You keep quiet; this is not your house!"*

*In addition some people do not register because...hmm...(chuckles)...if you pay the money...for example in my case , I paid \$30 at this clinic, but when I came here when I was in labour they said my labour was not progressing in terms of the centimetres of dilatation. 'You must go to Gomo and give birth from Gomo.' Yet there was not even a problem. Then I went to Gomo as said. And at Gomo I paid some additional money. Upon arrival (at Gomo) I was told that I had dilated eight centimetres. Yes. I delivered immediately upon arrival. Yet I had been transferred from here after being told that my labour was not progressing. And I had to pay eighty-six dollars at Gomo. They actually said they wanted cash. And the ambulance fee was twenty dollars. So one may deliberately delay, and only come when they are in labour. I will not pay any money beforehand, but will pay at the time of discharge from the clinic. That way, if I am transferred to Gomo I will still have my \$30 which I would not have paid, then I will use it to make the payment at Gomo.*

While it is possible that nurses may have made the referrals to the central hospital out of spite, it is more likely that the nurses made the decision to refer based on clinical criteria. However, it seems in these instances the nurses did not communicate their decisions clearly and courteously, and transferred women against a background of having already shouted at the client for 'bad behaviour', resulting in the client interpreting referral as a punishment. It appears from these interviews that nurses may have made conservative decisions about whether to refer the clients (it is better to be safe than sorry). However, it does not help the nurses' image (and will certainly confirm the client's suspicion that she has been spitefully referred) when, upon arrival at the more expensive hospital, the client is told that everything is alright and she gives birth without complication.

### ***Unassisted deliveries at the clinic***

Interviews indicated that due to the reluctance of nurses to assist labouring women when requested, many women had unassisted deliveries. Nurses were reported to have ignored women's cries that the baby was about to come out, resulting in the woman having to resort to having an unassisted delivery.

*...Then I waited, and waited and waited. Ah! I felt ah! This baby...I started feeling that the baby's head was coming out. That is when I went back to the labour ward, and they said, "Why have you come back here?" And I said 'the baby is about to come out.' ....And they said, "You are saying that the baby is coming out, do you know the process by which a baby comes out?" Ha-a so I then said...they said go back, and I said no. What I was now feeling was not good, so I climbed onto the bed. Then I...In the same room they had told me to leave. And they said this room is not one for leisurely sitting, go back to that room and sleep there. And I said, "No, Ambuya, please come and have a look, the baby is about to come out". Then I stayed there. That is when the waters broke when I was lying on that bed... I gave birth soon after the waters broke. They (nurses) were actually sitting there. Because the baby...I actually delivered the baby and it then...isn't it the baby...isn't it your legs will be positioned this way up, the baby then fell onto the bed, that is when she stood up and came.***19 year old mother of one**

This is obviously unsafe for both the mother and baby. Moreover, in this poor community where it is difficult to raise the required \$30 maternity fees and where women have to juggle

priorities, an unassisted delivery implies to the woman that she did not get good value for her money. This may make the same woman less likely to prioritise ANC registration during her next pregnancy. A 22-year old mother of two who reported that her sister-in-law had had an unassisted delivery in the antenatal ward in full view of other patients and their visitors had this to say: *“It makes you have a lot of thoughts like why should I pay the money if I am going to deliver by myself”?*

### ***Community awareness of nurses’ bad treatment***

There seems to be a lot of discussion in the community about the goings on at the clinic. Many participants reported that they had heard about the nurses’ bad treatment when they were out in the community. Women in the community were reported to discourage each other from going to the clinic in order to avoid bad treatment by nurses. A 19-year old woman reported being very disappointed to have the reports confirmed:

*My sister said ‘you shouldn’t have registered at that clinic because Mai T complained bitterly about that clinic.’ And I told her that a-a, unfortunately I can’t afford anything else...So I then realised it when I came here that she had been telling the truth. And so many people keep talking about it but I had ignored it...*

It is encouraging to note that not all nurses were discourteous; some participants reported that some of the nurses were very friendly and helpful: *“But the nurse who examined us later...that nurse was extraordinarily courteous.”*

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### **7.3.4 Unsupportive male partners**

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Another important finding is that as most women were financially dependent on someone, mostly their husbands, they did not have the power to decide when they would register for ANC. That decision mainly rested with the breadwinners, the husbands who were reported less likely to appreciate the importance of ANC: while women said they appreciated the value of the process of seeking antenatal care and knew what to do, men were viewed as not being supportive of the process, and were said to be concerned only about making sure that the woman delivered at the clinic i.e. they were only concerned with the point of delivery. Eight women reported that they had faced partner opposition to ANC registration. A twenty-five year old mother of one revealed that throughout her pregnancy her husband was not concerned that she had not registered, but then he had started panicking when she developed

abdominal pains which he construed as labour pains. Another woman said she felt men thought it acceptable for women to deliver at home: *“They will be saying that one can even deliver at home.”* Thus women would get negative responses when they asked for money for ANC fees, often being told that they would only be given the money towards the expected date of delivery:

*I think it’s because men do not really know the purpose of ANC registration. They just think that one registers so that she will give birth at the clinic. Because I kept telling my husband on a daily basis; he actually drank beer yet I was telling him that I needed money for registration. And he would say, “Why do you want to register the pregnancy when it’s still this small? You will register later isn’t it there is still plenty of time until you are nine months pregnant?”* **19-year old married mother of one**

In some cases the husband would say he did not have money yet it was apparent to the woman that he had it: *“He would get money but he would tell me that he doesn’t have it. Yet I could see it, but he would tell me that he didn’t have it.”*

Many women made pleas for the government to help them start income-generating projects that would allow them to make their own decisions about their own health. There was frustration with men for not being supportive for ANC, and a deep longing for the ability to make their own decisions about financial matters.

*If only there were things that one could do, for example if you can get some capital then you can start selling your things, then you will know that I have got my own money that I can use for whatever I want to do... There will be no need for you to wait for someone to give you money. Like in my situation, my husband had the money. But you can’t snatch it away or forcibly take the money from him because it is his money.* **19-year old married mother of one**

The main reasons that participants gave for their partner’s unsupportive behaviour were unawareness of the importance of ANC, as given above. In some cases, it appeared that the man’s assertion of authority played a significant part in his decision about ANC registration. Two women reported that their husbands did not allow them to register because they just wanted to show their power over them. The men seemed to get satisfaction that they were dictating what happens.

*He will say, "I will tell you what to do. I will tell you when to do what. I will say when you should do what. You will register when you are eight months pregnant."* **28 year old married mother of two, HIV negative**

*There were some people who wanted to help me but he would not allow me to get the money... he would say if you are ever given money by anyone you will be in for it.* **25 year old married mother of one, HIV negative**

In many other interviews, although the women did not explicitly describe their husbands as domineering, it was clear that the man's decision was not a point on which he was willing to negotiate.

Thirdly, there was indication that the fear of HIV testing played a role in the men's attitudes towards ANC registration. One twenty-six year old participant said she knew of a woman whose husband had not allowed her to register because he did not want her to get tested: "*Her husband hadn't wanted her to register because he said she was going to have a blood test.*" The fear of HIV testing is therefore an important deterrent for both women and their partners, which needs to be addressed. It again points to the polarised view of the ANC clinic as an HIV testing centre.

This gendered view is strengthened by the fact that mothers and mothers-in-law played an important role in getting the woman registered. Many women reported that it was their mother (or mother-in-law) that had brought about their eventual registration by providing the required ANC fees, and in the case of mothers-in-law, by pressuring their sons to give the registration money to the pregnant woman.

On the other hand, three women reported that their husbands had been supportive of ANC registration. Two of them seem to have acquired this appreciation through the pressure and encouragement that came from their extended family. The other man who was supportive of ANC had a strong desire to have an HIV negative baby, having gone for couple testing before pregnancy, and then encouraging his wife to register so that she could have another HIV test. These three cases highlight the fact that an intervention that is aimed at increasing the appreciation of importance of ANC among men (who are the financial decision makers) through encouragement and education may help in increasing levels of ANC registration among women. The men could be targeted through the points that seemed to have worked to

sensitise the three men on the importance of ANC: there could be interventions that promote the discussion of the importance of ANC among peers and families, including extended families, and interventions that promote couple counselling and testing for HIV. Once people know their HIV status, the fear of HIV testing will no longer be a barrier to ANC registration, as indicated by one of the three cases. As women are already aware of the importance of ANC, interventions that target them alone will be less effective than those that target men as well.

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### 7.3.5 Long waiting queues at the clinic

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Six participants reported that the ANC clinic was so busy that it prevented some women from registering. Participants reported that about fifty women come to the ANC clinic on any given day. The clinic visit would therefore take a long time. Typically, a woman needs to set aside the whole day for the clinic, which women reported was difficult for those who had to work.

*Some have a perception that antenatal care visits are a waste of time in that they say a-ah! Instead of going to the ANC clinic where I will spend the whole day sitting I would rather do something at home...they think it's a waste of their time...aha-a instead of...for example some people could have jobs to go to, and some have some vending to do at the market. So they will start thinking that oh no, who will stay at my trading table to sell my goods while I am at the clinic? I can't spend all that time sitting at the clinic. **19-year old married mother of one***

Another participant said she would ask for a few hours off work to get registered but each time she came to the clinic she found there were so many people that she could not get through within the short time that she had available. She would therefore go back to work without having registered, and she reported that she now found it difficult to keep asking her employer for time off work: *I would come. And I would find that there were many people at the clinic. So it became difficult for me to keep asking for time off from work. Then I didn't do it.* Even women who do not have to work might be filled with dread at the prospect of spending a long time at the clinic.

To manage the large numbers of clients the clinic operates an appointment system where women must first come and make an appointment for a day when they undertake the ANC

registration procedures. Participants reported that this was sometimes a problem because the appointed date could be weeks away, which further delays the registration. It is important that the community is made aware of this delay so that they factor it into their plans. Another challenge that this raised in the cash-strapped community was that often when the woman made that first visit it would be because she would have raised the \$30 registration fees. However she can only pay on the day of registration, not on the day she makes the appointment. This presents a challenge to some women in that if something urgent comes up they might use that money and when the appointed date finally comes the woman will no longer have the money.

*You will just be given an appointment date. So maybe when the appointed date comes you may no longer have that money. Yet you would have come before. Those are some of the things which cause delays, but one would have originally come on time. **27-year old married mother of four, HIV positive***

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### **7.3.6. Unintended pregnancy is a barrier to ANC registration**

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Five women reported that unintended pregnancies were not easy to get registered. Two participants who had unintended pregnancies reported that they had been on contraceptives when they got pregnant (one was on the pill and one on the injectable contraceptive). They both had not known that they were pregnant until late into the second trimester. They reported that this did not leave them with enough time to raise the ANC fees, so one of them did not seek ANC at all, and one registered late. The other challenge was with teenage pregnancies. Two participants had had teenage pregnancies while they were still at school. For both teenage mothers the period soon after discovery of the pregnancy was a difficult one where they tried to hide their pregnancy from their family and school authorities while at the same time trying to get the boyfriend to accept responsibility for the pregnancy. This all took a long time; as a result one of the teenage mothers delivered at home because she had not registered, and one registered late in the third trimester. The importance of preventing unintended or unplanned pregnancies therefore cannot be over-emphasized.

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### 7.3.7 Consequences of late registration/non registration

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#### **Detainment at the clinic after delivery**

The clinic allows women who have not registered to deliver at the clinic, but expects full payment before releasing the women to go home after delivery. As a result the woman is forced to find the money while she is still admitted, in some cases plunging the woman further into poverty as reported by this 29-year old, divorced, HIV positive participant who was explaining how she raised the required money before she could be discharged: *“I sold my bed. There was somebody who was at home (while I was at the clinic) who sold the bed for me. Then she came and paid.”*

#### **Home delivery**

One of the consequences of failure to raise the ANC registration money was delivery at home. Two of the 21 interviewed women delivered at home. They both reported that they had had no money to register for ANC. Importantly, both these women had not planned to deliver at home, but had throughout their pregnancies been hopeful that they would get the money from somewhere and register for ANC.

*That’s not what I had planned...I was hoping that I would register like other people; and go to routine antenatal care visits as others do. E-e, and also deliver in the hospital to ensure that if there are other things which have...any challenges, I may get help.*

Both women who delivered at home reported that they had had unpleasant experiences delivering at home, and wished they had delivered at a health care institution. One of them, a seventeen year old participant, reported that she had been very scared when she delivered because the baby had had the cord around his neck when it was born. She reported that her grandmother, who assisted the delivery, was quick to slip the cord over the baby’s head but the participant was really scared and wished she had professional help. She sustained a tear during delivery but there was nothing she could do about it except wash with salt:

*It is better (to deliver in a health care institution) in case one needs to have stitches done...if you deliver at home and you have a tear you will just remain like that...Interviewer: So did your grandmother tell you what to do now that you had had a tear? Participant: A-a, I was just told that I needed to wash with salty water.*



Seven other interviewed participants knew of someone who had delivered at home because they could not afford the ANC fees. One participant reported that she knew of a woman who had died after she had delivered at home in Mbare:

*She had delivered at home, in the evening. And she died on the morning of the following day...she thought she was okay...so the following morning it is said that she actually woke up and swept the yard. Then she made her tea and drank it. And it is said that when she was still having breakfast she just said, "A-a, my head." And she kept crying out about her head until she died.***28-year-old married mother of three.**

***HIV negative***

Of note, both interviewed women who had delivered at home (and the woman described above who died after delivering at home) did not seek any medical care afterwards. Although many women who have not registered choose to go and deliver at the clinic, others choose to deliver at home because they know that the clinic will still require the \$30 maternity fees, which they cannot afford.

As a solution women have resorted to employing the services of traditional midwives who can assist at a home delivery. The traditional midwives are known to ask for less money than the clinic.

*Interviewer: Do they (traditional midwives) not ask for money for their services?*

*Participant: They do ask for money, but they just ask for whatever you can afford.*

*They just say give me any amount you can.***34-year old married mother of three, HIV negative**

*Maybe (they do not register at the clinic) because they have heard of other places which ask for less money; the traditional midwives who are present in the community. They ask for ten dollars.***16-year old married mother of one, HIV negative**

## 7.4 SUMMARY OF STUDY FINDINGS

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This qualitative study revealed six barriers to ANC registration: user fees, fear of HIV testing, nurses' discourteousness, unsupportive male partners, long waiting queues at the clinic and unplanned pregnancies. User fees were reported to be the main barrier to ANC registration. In

the ultra-poor community that the women came from, the \$30 required for user fees was an unaffordable amount.

Although user fees were reported to be the main barrier to ANC, there was evidence that there were other important barriers which participants may have found more difficult to admit to, namely fear of HIV testing and nurses' discourteousness. While user fees and unsupportive male partners were seen to offer a barrier that was beyond the participant's control, there was a view that it was unacceptable to stay away because of the fear of HIV testing or fear of bad treatment by nurses probably because women understood it was important to have ANC and it was seen as cowardly to risk jeopardising the pregnancy out of fear. Although good rapport was established with participants and a non-judgemental attitude was adopted throughout, aware that they were being interviewed because they had not registered or had delayed registering, it is possible that participants may have felt that they were being viewed (or viewed themselves) as bad mothers. This may have influenced the participant to use the interview to create another identity of themselves for the interviewer i.e. one of a responsible mother who faced insurmountable barriers to ANC registration. Identity creation is recognised to happen in interviews<sup>116,140</sup> where participants use the interview to paint a picture of themselves that they want the interviewer to see. It can also be because this is the view that the participant wants to have of herself because it is too painful to think otherwise. For example, in a study exploring syringe and needle sharing among injection drug users most interviewed participants reported that everyone else besides them shared needles, and they were the exceptions who behaved responsibly.<sup>141</sup> Understanding the reasons why a participant chooses to present themselves in a certain light may offer us greater understanding of the phenomenon that is under study.

The findings and implications of this qualitative study will be discussed in detail in the Discussion Chapter.

## CHAPTER 8: ATTENDANCE AT SIX-WEEK POST-NATAL VISIT AT MBARE CLINIC

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### 8.1 OVERVIEW

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In this chapter I explore the facilitators and barriers to women's attendance at the six-week post-natal visit. The chapter comprises results from three studies:

i) *Retrospective clinic record survey*. This study was conducted in order to explore six-week visit attendance according to HIV status. Briefly, clinic records of women who delivered at Mbare Clinic between 15 November 2011 and 12 December 2011 were reviewed to extract information on their six-week visit attendance. Logistic regression was performed to investigate what participant factors were associated with six-week visit attendance.

ii) *Follow-up study of HIV positive women at six weeks*. In this study HIV positive women who participated in the delivery survey were followed up at six weeks post-natally in order to explore attendance rates and uptake of paediatric cotrimoxazole prophylaxis.

iii) *Qualitative study of barriers to six-week visit attendance*. In this study women who took part in the delivery study, but then failed to attend for their six-week visit appointments were followed-up by study staff and asked to participate in in-depth interviews where their reasons for non-attendance were explored. Interviews were analysed using thematic analysis.

The information from these three sources were triangulated to piece together a picture of the facilitators and barriers to attendance at the 6-week post-natal visit.

### 8.2 RESULTS OF RETROSPECTIVE STUDY OF SIX-WEEK VISIT ATTENDANCE

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333 women delivered within the period covered by the record review (15 November-12 December 2011). Table 8.1 shows their characteristics. 167 (51%) participants were residents of Mbare. 235 (71%, 95% CI 65.6%-75.5%) had registered for ANC. This ANC registration rate was lower than recorded in the delivery survey (Chapter 6 - 76.6% (95% CI 72-81), although there was a slight overlap in the confidence intervals. The delivery survey was conducted only among Mbare residents and it included women who had registered for ANC in other health care centres than Mbare Clinic, but the clinic records only captured Mbare Clinic registrations. The mean age of the participants was 25.3 (24.8-25.9) years and the age

distribution is as shown in Table 8.1. Thirty four (10.2%) were HIV positive, 222 (66.7%) were HIV negative and 77 (23.1%) were of unknown HIV status.

Among women who delivered at Mbare Clinic during this period there was no association between ANC registration and where they lived on chi-squared analysis. As for the delivery survey there was no association between ANC registration and age (Chapter 6). However there was strong association ( $p < 0.001$ ) between ANC registration and HIV status: 68% of women who did not register for ANC had unknown HIV status, compared with 4% among those who had registered. There was strong association ( $p < 0.001$ ) between age and HIV status with HIV prevalence of 7.3%, 6.0%, 5.7% in the 15-19, 20-24, 25-29 age groups but 28%, and 24% in the 30-34 and 35-39 age groups respectively.

Sixty-five (19.5%, 95% CI 15.2%-23.8%) women attended their six week post natal visit. 26, 31, 7 and 1 attended when the baby was 5, 6, 7, and 8 weeks old respectively. In univariable analysis, ANC booking status, area of residence and unknown HIV status were strongly associated with six-week visit attendance (Table 8.1). The strongest association was with area of residence: residents of Mbare were twelve times more likely to attend the six-week visit than those who were non-resident, odds ratio 11.8 (4.8-28.7).

**Table 8.1: Participant characteristics and association with six-week visit attendance**

Characteristic	N (%)	N (%) attended six- week visit	Odds ratio and 95% CI	p-value
<b>ANC Booking Status</b>				
Booked	235 (70.6)	56 (23.8)	3.1 (1.5-6.5)	0.003
Unbooked	98 (29.4)	9 (9.2)	1	
<b>Area of residence</b>				
Mbare	162 (49.2)	58 (34.7)	11.8 (5.2-26.8)	<0.001
Non-Mbare	167 (50.8)	7 (4.3)	1	
<b>Age</b>				
15-19	41 (12.3)	9 (22.0)	1#	
20-24	117 (35.1)	28 (23.9)	1.1 (0.5-2.6)	0.8
25-29	106 (31.8)	18 (17.0)	0.7 (0.3-1.8)	0.5
30+	69 (20.7)	10 (14.5)	0.6 (0.2-1.6)	0.3
<b>HIV Status</b>				
Positive	34 (10.2)	8 (23.5)	1	
Negative	222 (66.7)	50 (22.5)	0.94 (0.4-2.2)	0.9
Unknown	77 (23.1)	7 (9.1)	0.3 (0.11-0.99)	0.05

# Score test for trend, p=0.2

In multivariable analysis, the final model had ANC booking status, area of residence, and HIV status (Table 8.2). In the adjusted model, only ANC booking status and area of residence were associated with six-week visit attendance; after taking account of ANC registration status there was no association between HIV status and six-week visit attendance.

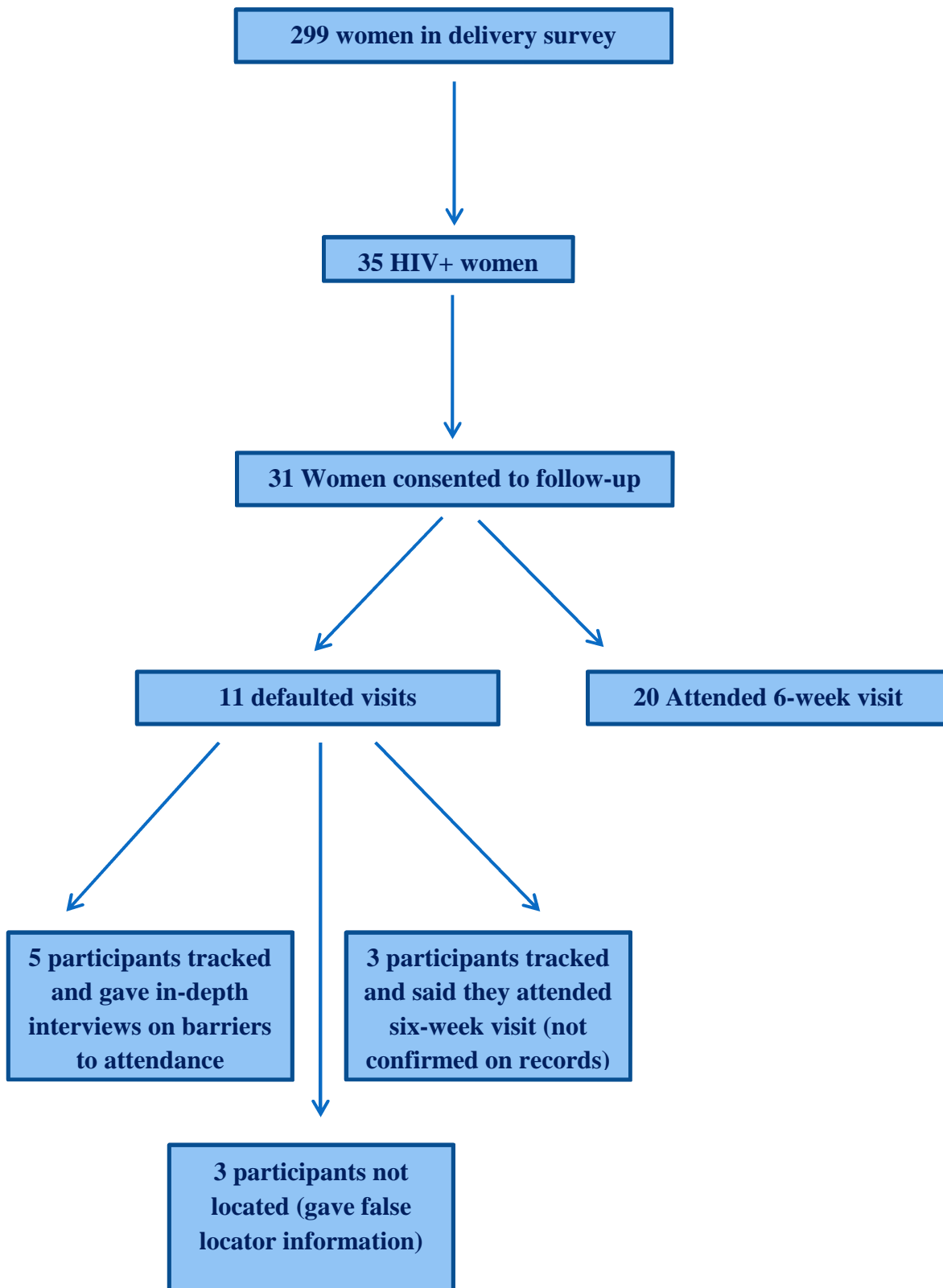
**Table 8.2: Multivariable analysis of factors affecting six-week visit attendance**

Characteristic	Adjusted odds ratio (95% CI)	P value
<b>HIV status</b>		
Positive	1	
Negative	1.1 (0.4-2.8)	0.88
Unknown	0.7 (0.15-2.8)	0.57
<b>ANC booking status</b>		
Unbooked	1	
Booked	2.9 (1.01-8.4)	0.05
<b>Area of residence</b>		
Mbare	13.3 (5.8-30.6)	<0.001
Non-Mbare	1	

### **8.3 PARTICIPANT ATTENDANCE OF SIX-WEEK VISIT**

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Of 35 HIV positive women who took part in the delivery survey described in Chapter 6, 31 consented to follow-up at the-six week visit. The main reason given by the four women who declined follow-up was unwillingness to be visited at home due fear of disclosure of HIV status. Of the 31 women who consented to follow-up, 20 attended the six-week visit as scheduled; see figure 8.1 for details of six-week visit attendance.



*Fig 8.1: Six-week visit attendance of 31 HIV positive study participants*

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**8.3.1 Prescription of cotrimoxazole prophylaxis for HIV-exposed infants**

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The clinic operates a Chronic Diseases Clinic where all patients with chronic diseases including HIV positive patients and HIV-exposed infants are evaluated on a regular basis, (usually monthly). After the six-week post-natal visit procedures for the mother, she is referred to the chronic diseases clinic where the infant is supposed to be registered in the HIV-exposed infant register that is kept at that clinic, be initiated on cotrimoxazole prophylaxis and have a dried blood spot sample taken for early infant diagnosis by DNA PCR. At that point a hand-held medical record card for the HIV-exposed baby is also created; all subsequent monthly evaluations and prescriptions of ARV and cotrimoxazole prophylaxis will be documented on this card.

Among the twenty women who attended the six-week visit, thirteen had their babies initiated on cotrimoxazole prophylaxis as scheduled. Five infants were not initially prescribed cotrimoxazole for various reasons; study staff investigated the reasons and assisted the participants to have cotrimoxazole prescribed. This investigation was facilitated by the good relationship that was between the study nurse and the clinic nurses. The study nurse had previously worked within the City of Harare system, so she was personally known by many of the nurses who were then able to open up to her about the reasons why cotrimoxazole had not been prescribed. Figure 8.2 describes the reasons that cotrimoxazole prophylaxis was not prescribed for the five women. The reasons included oversight by the nurse who was supposed to prescribe cotrimoxazole, stock-outs of cotrimoxazole, and failure of appropriate referral of women to the place where cotrimoxazole was to be prescribed. In addition, two women deliberately chose not to get cotrimoxazole, and their reasons are also documented in figure 8.2.



<p><b>Participant 1</b></p> <p>The nurse who saw the participant at the six-week postnatal visit said she did not refer her to the chronic diseases clinic because she had assumed the participant already knew she was supposed to go there.</p>	<p><b>Participant 2</b></p> <p>Prescription/referral for cotrimoxazole prophylaxis was overlooked by the nurse who examined the participant at the six-week postnatal clinic</p>
<p><b>Participant 4</b></p> <p>Cotrimoxazole was out-of stock</p>	<p><b>Participant 3</b></p> <p>Nurses gave the participant another appointment date (without prescribing cotrimoxazole) because they did not have the materials required for DBS sample collection in stock.</p>
<p><b>Participant 5</b></p> <p>Cotrimoxazole had previously been out of stock. It was in stock when the prescription was written for this participant but it was not dispensed because it had not yet been entered into the stock cards.</p>	
<p><b>Participant 6</b></p> <p>She was accompanied to the six-week visit by her husband. She had not disclosed her HIV status to her husband, and because she was afraid that he would discover her HIV status she left before cotrimoxazole was prescribed for the baby. Upon follow-up by study staff she indicated that she was not going to seek any HIV-related care for herself or baby because she did not want her husband to discover her HIV status.</p>	
<p><b>Participant 7</b></p> <p>The participant said when she came to the six weeks visit one of the other mothers who was sitting next to her in the queue told her that cotrimoxazole prophylaxis is only given to HIV positive babies. Because she and her baby had taken some ARV prophylaxis she believed that her baby was HIV negative, so she did not get cotrimoxazole for her baby.</p>	

*Fig 8.2: Reasons why cotrimoxazole was not initiated among women who attended six-week visit*

## 8.4 QUALITATIVE FINDINGS ON BARRIERS TO 6-WEEK VISIT ATTENDANCE

Interviews were conducted among five women who failed to attend the six-week visit. These women had been recruited into the delivery survey described in Chapter 6 and agreed to follow up at 6 weeks then failed to attend. Table 8.3 shows the characteristics of the five women.

**Table 8.3: Characteristics of interviewed participants**

Pseudonym	Age (Years)	Marital Status	No of children	ANC Registration	Age of baby at interview (months)
Mercy	33	Married	Three	Registered	Three
Chido	27	Married	Three	Not registered	Five
Esther	Missing	Married	Three	Registered	Four
Linda	32	Married	Three	Registered	Three
Rudo	23	Single	Two	Not registered	Seven

Two main barriers to attendance at the six-week visit emerged: 1) lack of appreciation of importance of visit, and 2) distrust of the health care system, particularly distrust of nurses.

### 8.4.1 Lack of appreciation of importance of six-week visit

All participants knew about the six-week visit; it was known as a visit where postnatal women are physically examined and offered family planning services. At the beginning of the interviews, when participants were asked to talk about their reasons for non-attendance, four gave personal reasons: Chido said she had gone to a funeral, Linda said she had been attending court after her husband was arrested for theft, Esther said she had been menstruating and had assumed nurses would not examine her because of that, and Rudo said she had relocated to rural areas because she could no longer afford to live in Harare, and the rural clinic was too far to walk to. Chido, Linda and Esther reported that they could not come to the clinic after the appointment date because they assumed nurses would not accept them; there was a belief that a woman could not be re-scheduled if she had missed her appointment:

*I thought that even if I came they would not help me because they will be helping those who had appointments for that day. That is their rule at the clinic. If you miss your appointment next time they will be helping those who have current appointments; defaulters are not accepted. **Chido, 27-year old mother of three***

It was apparent from the interviews that all five women placed little value on the maternal health services that are provided at the six-week visit. None of them seemed bothered that they had missed these services. Indeed, they expressed the view that women hated the physical examinations that are a part of the six-week visit procedures, and they did not see its value.

*Some say they don't like to come and have that object...you know that object that they listen through to determine whether you are pregnant again...that thing which they place on your tummy and then they bring their ears close to listen. People say they don't like that. And some say they do not like having fingers inserted down there. **Chido, 27 year old mother of three***

*Some women do go...But I am just lazy...some do go. Some women really think it is important...but I say, "No, it's not like I am sick, so why should I go?"...I am the one who did not think it was important...My mother did ask me about the six-week visit, and I said, "Ha-a, why should I go. What does it matter? **Rudo, a 23-year old mother of two***

As the interviews progressed it emerged that none of the women except one (Mercy) knew that in addition to maternal health services there were services for HIV-exposed infants provided at that visit. When they missed the six-week visit, they assumed that they had only missed out on maternal health services, and had not known that in addition they had missed out on services that were meant for their babies. There was shock and disappointment when study staff pointed out that the baby was supposed to have been initiated on cotrimoxazole prophylaxis at six weeks. Women blamed the clinic nurses for not telling them this information, insisting that if they had known about the infant services they would have attended:

*I would have come. I really would have come. I just thought all there was to it (six-week visit) was the examination and being given family planning pills. I did not know that it was for the baby. Esther, married mother of three (age not given)*

That women valued child health services was supported by the fact that all women (except Rudo) attended the child health clinic regularly, and their baby immunizations were up to date. The obstacles to six week visit attendance that had been mentioned earlier became surmountable when the welfare of the baby was considered. This teaches us three things: women may face various personal obstacles that prevent them from taking up their appointments, so health care systems should have clear procedures of how to re-book missed appointments and communicate this to all clients. Second, if a woman thinks a visit is important, she will probably do all she can to overcome her personal obstacles and ensure attendance. This highlights the importance of education in ensuring uptake of services. Third, all these women would have prioritised their babies health over their own.

There was a strong view that nurses did not educate women enough about available services for HIV-exposed infants. Only one participant, Mercy, had known that there were infant services that were to be provided at the six-week visit; in fact her knowledge of HIV and PMTCT services was strikingly extensive. But she had not obtained her education from Mbare Clinic; she was enrolled in an ART programme at a Médecins Sans Frontières (MSF) clinic in Epworth, where she reported she had got all her information. When discussing this point she had added that she noticed that not much education on caring for HIV-exposed infants was given at Mbare Clinic:

*Ever since the time I enrolled into this clinic, I have not received any PMTCT education. I have never...I think I have been coming for antenatal care since September; there was never a day I was given PMTCT education. I don't know if it's because they thought I have...I am already on medication (ARVs) so maybe they assumed I already knew, I don't know. Mercy, 33-year old mother of three*

The same participant called on nurses to improve on patient education on PMTCT:

*I think we should educate each other, really. These PMTCT issues are important. They (nurses) should not just concentrate on touching our tummies because that tummy is not important, what is important is what will come out of it, really. We want it to live. Mercy, 33-year old mother of three*

Although it was clear during the interviews that nurses had not told the study participants about the infant services at six weeks, it was also apparent that the participants had not been totally ignorant of these services. Chido had friends whose babies were on cotrimoxazole prophylaxis, and both Esther and Rudo had heard other people in the community talk about it. But it was unclear to all three of them when and how they could access the cotrimoxazole prophylaxis. Of note, although they had been in regular contact with nurses at the child health clinic and when seeking treatment for her sick baby (Chido) none of them had felt able to ask the nurses about how to access HIV-related care. This will be discussed in more detail in the next section.

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#### 8.4.2 Distrust of nurses

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As discussed above, there was one participant, Mercy, who was aware of the services for HIV-exposed infants, having received education from the MSF clinic where she was attending for her own HIV care. She reported that she chose not to come back to the six-week visit because she did not trust the nurses at Mbare to provide the correct services for her baby as they had failed her at time of delivery: they omitted to give zidovudine prophylaxis to her baby; they only gave nevirapine. She reported having been aware that the nurses were supposed to give zidovudine in addition to single dose nevirapine to her baby, but when they did not she had not felt able to tell or ask the nurses for fear that they would not receive this positively. At six weeks she attended the MSF clinic where the baby got the appropriate services, but she did not get the maternal health postnatal services because they were not being offered there.

*So I started to think about it a lot, that a-a, I registered (for ANC), and it was not a mistake to register. I wanted for my baby...to save my baby. But why then did they not provide me with the full package of services that the baby was supposed to get, yet others are said to get it? That's why I lost heart and did not return at six weeks. Then I changed to another hospital...*

*...It is not easy to open up about your HIV status, yet we opened up because we knew that was the way to save the coming babies. So it is painful that I opened up, they did not force me, I opened up by myself. Then they did not do all the stages I expected they would do for my baby. So I thought they let me down...*

*....I actually knew what my baby was supposed to get, but I was not able to demand it. Most of the time I believe that if someone is doing her job and you look like you want to teach them the job they will lose their temper. That is what I was afraid of...*

***Mercy, 33-year old mother of three***

This participant was not the only one who felt unable to ask for specific help from the nurses. Chido had wanted PMTCT services for her baby at time of delivery but had not felt able to ask. She had not registered for ANC and reported that nurses gave her a “cold shoulder” because of that. They had ridiculed and taunted her about not having registered. In an effort to get HIV-related care for her baby, she had tried to tell them that she had been tested for HIV previously, but they had dismissed her without even asking what the test result had been, telling her she was lying about having been tested. As a result she felt belittled and unable to say anything; *“Those things really affected me, I felt hurt but there was nothing I could do.”* She had silently hoped that they would test her since they thought she was lying about having been tested. As a result she did not get any HIV related care for herself or her baby.

*In my mind I thought, a-a, since they are saying I am lying...I expected that they would come back and offer to test me. But they did not say that. I was eventually discharged without being asked about it again...*

*...I did not ask them to test me because I was now feeling guilty that I...they would think I was a nuisance. So I just wanted...I just told myself that ha-a, let me just...let me ignore everything and concentrate on getting out of here... **Chido, 27 year old mother of three***

Chido, Esther and Linda had been in regular contact with the clinic after delivery, bringing their babies for treatment and child health visits. They all had questions about how and when they could access cotrimoxazole prophylaxis for their babies, but none of them had felt able to ask the health care workers. What was striking is that despite these three women’s regular contact with the clinic, the nurses did not recognise the HIV-exposure status of the infants, so they did not offer them any HIV-related care.

Another finding was that in some instances, the nurses could not be trusted to keep a patient’s HIV status confidential. Linda, one of the participants who had been in regular contact with the clinic said when she came to the one-month and two-month child health visits the nurses

did not offer any HIV-related care to the baby (and she did not ask as described above). On the third month she had asked her aunt to bring the baby to the child health clinic. It was at this visit that the nurses realised from the child health card that the baby was HIV-exposed, and they disclosed this fact to the aunt. The aunt had not previously known about the participant's HIV status. The participant was hurt that the nurses had taken it upon themselves to disclose her HIV status.

*Instead of disclosing to my aunt like that it would have been better if they had said, "We are not going to examine this baby until the mother comes here herself. **Linda, 32-year old married mother of three***

Although the nurses had sent a message through Linda's aunt that she should come and see them about getting the baby initiated on cotrimoxazole, she had not yet been to see them, but had instead self-prescribed the cotrimoxazole prophylaxis. She said she had had left-over cotrimoxazole from a previous prescription and after the aunt's visit had decided to start using that for prophylaxis. She appeared to resent the nurses for the breach of confidentiality, and although she promised to go and see the nurses as they had requested, her promise was not convincing. She refused further follow-up from study staff.

Chido (the participant who reported that she had been ill-treated by nurses at delivery) also reported reluctance to approach the nurses about HIV-related care for herself and her baby. She reported that her experience with nurses at delivery had discouraged her. In addition, she said that she had an aunt who worked at the clinic and she feared that the nurses would disclose her HIV status to her aunt. She reported that she grew up in an unstable family environment and that her grandmother's family kept chasing her away from home because she was an illegitimate child. She confided that she had been involved in a lot of risky sexual behaviour in the past, and her aunt who works at the clinic insulted her about it and kept telling the whole family that she would die of AIDS:

*So you know if you are constantly chased away from home you find that you really have nowhere to go because nobody loves you. So sometimes I ended up in beerhalls, participating in whatever was happening at that time. So because I would go to the beerhalls she (aunt who works at clinic) would start saying, "He-e!...She has AIDS. She is going to die before December." For the past three years she has been saying I will die. **Chido, 27 year old mother of three***

Chido had never told anyone in the family that she had HIV, and she did not want her aunt to know. It could be the combination of her unstable social background (including unloving family) and ill-treatment by nurses which decreased her feelings of self-worth resulting in diminished desire for health-seeking. She refused to discuss HIV-related care with the nurses despite attempts by study staff to get her private appointments with the Sister-in-charge. Upon further follow-up study staff discovered that Chido's baby had later died.

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#### 8.4.3 HIV care for the participants themselves

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Only one participant, Mercy, who was enrolled at the MSF clinic, was receiving appropriate care for herself; she was already taking ART. The other four women had not had their disease status assessed; i.e. they had not yet had CD4 counts and had not been to the ART initiation hospital for assessment. Esther was referred to clinic nurses after the in-depth interview, but Chido and Linda were not successfully referred as described above. Linda, the woman who had self-prescribed cotrimoxazole for her baby, instead asked if she could get ARVs from her husband whom she reported worked in the army and had access to them. She was discouraged from doing this, but her reluctance to speak to nurses and her history of self-prescription was worrisome. The fourth woman, Rudo, was not interested because she believed in spiritual healing, and that was the avenue she was pursuing:

*There is a church I have been going to; there is some water that is offered there. It is an Apostolic church, and the water they give is called blue water... It is used for treating HIV; they say it completely cures HIV. **Rudo, a 23-year old mother of two***

From her description, the 'prophets' at her church make the blue water by dissolving a blue powder they purchase in pharmacies (most likely this is copper sulphate which is sold in pharmacies for use as an algacide in swimming pools). Rudo reported that the blue water was toxic, and emphasized that it should only be used under supervision of the 'prophets' who know the proper dosage: *"It is toxic; it is intoxicating, it can wear you out."*

There is a time when she (Rudo) was prescribed cotrimoxazole prophylaxis for herself, but she reported that she did not like the side effects, so she stopped taking it and started giving it away to anyone in the rural home who was not feeling well:



*I would give the tablets away. If someone came and was not feeling well, I would give it to them. Because in my rural home that is the drug that people enquire about the most; mostly they will ask you if you have cotri. Because it is said to be powerful....You can take it for a headache...you can just take it for a day or two...*  
**Rudo, a 23-year old mother of two**

### 8.5 SHORT DISCUSSION OF FINDINGS

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There is poor attendance of the six-week visit; overall only a fifth of women return for six-week visit procedures. Six-week visit attendance was not associated with HIV status. Some of the HIV positive women who did attend the six-week visit did not receive prescription for cotrimoxazole prophylaxis for their babies for various reasons including omission by clinic nurses, stock outages, and fear of disclosure of HIV status. Qualitatively, the main barriers women described to six-week visit attendance are lack of appreciation of importance of visit for the infant (there was perception that the visit would only benefit the mother, not the infant), and distrust of clinic nurses.

As expected, six-week visit attendance was associated with area of residence, with more women from Mbare attending. It is anticipated that women who do not reside in Mbare will attend their local clinics in their respective places of residence. There is still unacceptably low attendance if we consider only the Mbare residents: only 35% of them attended the six-week visit.

Poor postnatal visit attendance is not limited to Mbare; there is general poor attendance of the six-week visit in Zimbabwe, with overall attendance rates of 25.9% and 31.0% in Harare and Chitungwiza Provinces and a national average of 44.5%.<sup>142</sup> This low percentage has been noted as a cause for concern in the most recent Zimbabwe National Health Profile<sup>142</sup>, and the need to identify barriers has been expressed. Addressing some of the barriers that were uncovered in this study might help increase attendance rates.

ANC was associated with nurses' awareness of infant HIV exposure status: nurses did not know the HIV status of 68% of women who did not register before delivery compared to only 4% of women who had registered. This shows that nurses were not systematically implementing procedures to test all women presenting in labour with unknown HIV status,

despite national recommendations/guidelines to do so. Clearly these systems need to be strengthened to ensure that appropriate care is given to all mothers and their babies.

Non-attendance of the six-week visit limited the opportunity for women to get their own HIV care: only one of the five interviewed women was receiving appropriate HIV-related care for herself (and it was being provided through a separate health system); the other four reported that they had not yet been examined to determine HIV disease progression. WHO has made strong recommendations for linkage to care of women who are tested during pregnancy<sup>49</sup>; Zimbabwe has adopted the guidelines and they were being implemented at Mbare Clinic. It is clear that the importance of the six week visit needs to be emphasised. To promote attendance of the six-week visit, the Zimbabwean health care system in conjunction with donors might consider introducing conditional cash transfers to households; conditional on attendance of preventive maternal and child health services. Recently conducted systematic reviews have demonstrated the positive impact of conditional cash transfers on attendance of preventive health services in low and middle income countries.<sup>143,144</sup> Zimbabwe has recently introduced unconditional cash transfers to the poorest households<sup>145</sup>, but unconditional transfers may not result in positive health behaviours as has been demonstrated for conditional transfers<sup>143</sup>. Another method that could be employed to incentivise attendance of the six-week visit is to reduce hospital fees for women who have attended the six-week visit in the event that they fall sick. Such a system is already being implemented among children in Harare, and could be contributing to the good uptake of child health services (a child who is under five who falls sick is treated for free on condition that s/he attends regular child health visits).

One method that can be employed to increase the quality of services provided is continued training to ensure that all nurses are aware of the PMTCT implementation procedures so that there are no omissions. Health care workers (including non-clinical staff) should also be trained to ensure that they are ambassadors of the clinic even in the communities that they live in. Evidence from this study is that women pick up a lot of information that is discussed in communities. Health care workers are likely to stand out as a knowledgeable voice that members of the general public will listen to. It is therefore important that they carry messages of hope and encouragement for people living with HIV, and ensure that people are aware that HIV transmission to HIV-exposed infants can be prevented. If Chido's aunt had been more positive in her communication she may have instilled more confidence and hope in her, which may have encouraged Chido to seek her baby's health care.

Another worrisome finding is the improper use of drugs that was reported to be happening in the communities, including the self-prescription of cotrimoxazole prophylaxis, sharing cotrimoxazole tablets and likely, ARVs as well, and use of potentially toxic chemicals by the Apostolic group. Not only will improper drug use harm the users but there could be an increase in microbial resistance which will render many of our first choice anti-microbial drugs ineffective.

A list of recommendations resulting from this chapter is given below:

1. Because women find it difficult to come to the clinic if they have missed an appointment (because of the belief that they will not be attended to), health care centres should have ways of re-booking attendees/patients who have missed their appointments.
2. There is need for education of women on the importance of the six-week visit, both for the mother and for the baby:
  - i. Women need to be taught on how attendance of the six-week visit will benefit their own health.
  - ii. They also need to be taught on available PMTCT services for HIV exposed infants.
3. City of Harare or Ministry of Health might consider incentivising attendance of the six-week visit, e.g. by commissioning conditional cash transfers (conditional upon attendance of the six-week visit), or reducing hospital fees for women who have attended the six-week visits.
4. Nurses who provide child health services need to pay close attention to the HIV exposure status of the infants they attend, and also need to ensure that HIV exposed infants are getting the necessary care. If the HIV-exposure status of the infant is unknown, nurses at the health care centres need to test the baby to determine the HIV-exposure status. Ministry of Health have already issued these guidelines, and it is important that they find ways of ensuring that the guidelines are followed.
5. The findings in this and other chapters show that clients find nurses unapproachable and unsympathetic. Nurses need to be trained on good client services. City of Harare might need to do more to ensure that nurses treat patients/attendees well, e.g. by rewarding health care workers who treat clients well and disciplining those who do not.

6. The fear of unwanted HIV disclosure prevents uptake of HIV care services. Nurses need to be reminded (or trained) on the need to maintain confidentiality of HIV status as they carry out their duties in the various clinics, particularly at the child health clinic where there is little privacy during consultations.

The findings presented in this chapter will be discussed more fully and in light of other findings in the Discussion chapter.

## **CHAPTER 9: QUALITATIVE FINDINGS ON ADHERENCE TO COTRIMOXAZOLE PROPHYLAXIS**

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### **9.1 OVERVIEW**

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In this chapter I describe results of a study that was conducted to explore issues affecting the ability of HIV positive women to keep their babies on cotrimoxazole prophylaxis. All willing HIV positive women who participated in the cross-sectional survey at time of delivery (or who were recruited after the survey ended) and whose babies had been prescribed cotrimoxazole prophylaxis at six weeks were invited to participate in this adherence study. They were enrolled to be longitudinally followed-up at 3, 4, 5 and 6 months. During the monthly visits they completed a short interviewer-administered questionnaire about adherence to cotrimoxazole. At between 4.5 to 5 months they were interviewed in-depth about their experiences of keeping the baby on cotrimoxazole. In addition, they were visited at home to investigate how well they were measuring the prescribed dose of medicine. To ascertain this, staff took a bottle of cotrimoxazole suspension to the participant's house and asked her to measure the amount of cotrimoxazole she would normally give to the baby, using the measure/utensils she typically used. In this chapter the main findings presented are the qualitative in-depth interview results, but additional information that was gathered during longitudinal follow-up will be included to illustrate or provide support to the qualitative study findings. The findings from the home assessments will also be presented.

Written informed consent was obtained from all women before participation in the longitudinal study. All participants who were being longitudinally followed in the adherence study agreed to participate in the adherence qualitative interviews. In-depth interviews were conducted by the candidate in Shona (the local language in Zimbabwe), in private, in a closed room at Mbare Clinic. The interviews were digitally recorded, transcribed and analysed according to thematic analysis.

### **9.2 DESCRIPTION OF STUDY PARTICIPANTS**

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Twenty participants participated in the adherence sub-study. Most (17) were married and majority were multiparous (Table 9.1). Twelve were diagnosed with HIV during their most recent pregnancy, four in previous pregnancies and three had been diagnosed as a result of theirs or their children's illness. All participants came from poor families; they either earned

no income or earned very little from self-employment, mainly vegetable vending in the nearby market.

**Table 9.1: Characteristics of interviewed participants**

Pseudonym	Age (Years)	Marital Status	No of children	Timing of HIV diagnosis	Occupation
Tari	30	Married	4	During ANC, at 3 months	Sells vegetables
Grace	23	Married	2	During ANC	Not employed
Blessing	35	Married	3	During ANC, at 6 months	Sells vegetables
Saru	36	Married	2	Previous pregnancy, 2009	Not employed
Maggie	33	Married	3	During ANC, at 9 months	Sells vegetables
Rumbi	33	Married	2	Previous pregnancy, 2003	Not employed
Miriam	37	Married	4	During ANC, at 6 months	Sells vegetables
Fungai	27	Married	3	During ANC, at 8 months	Not employed
Mucha	41	Divorced	5	2005 when she was sick	Meat vending
Irene	19	Single	1	During ANC, at 6 months	Not employed
Sekai	35	Married	3	During ANC, at 7 months	Not employed
Ruth	23	Married	1	Previous pregnancy, 2009	Not employed
Nyari	24	Married	2	VCT, March 2010	Not employed
Maka	24	Married	3	During ANC, at 8 months	Meat vending
Tracy	29	Divorced	3	Tested at delivery	Dancer
Vimbai	33	Widow	5	During ANC, at 8 months	General vending
Tendai	27	Married	4	2008, child was sick	Sells vegetables
Barbara	23	Married	1	During ANC, at 6 months	General vending
Vongai	32	Married	2	2007, when she was sick	Sex work
Stacy	35	Married	4	Previous pregnancy, 2008	Sells vegetables

The women lived in crowded accommodation, where it was common to find several people (or more than one family) residing in a single room of less than twenty square metres. Most participants lived in flats which were originally built for bachelors. Each family occupied a single room as stated above, with shared toilets and bathrooms at the end of the corridor (shared by more than 30 families living on the same floor). Sometimes up to 4 families share one room. An example of such a flat is shown in Fig 9.1 below. This kind of accommodation

had an influence on how women felt about their HIV diagnosis and their health-seeking behaviour, as will be described later in this chapter.



*Fig 9.1: Picture of Matapi Flats in Mbare*

All women-infant pairs were enrolled at Mbare Clinic where their babies were being followed-up for cotrimoxazole prophylaxis (and extended nevirapine prophylaxis for women who enrolled after this was incorporated into the national guidelines). They collected their prescription refills from the chronic diseases clinic at Mbare clinic as described in Chapter 8.

Before discussing the study findings in detail, two case studies will be presented in order to give a wider picture of the context of the women's lives.

**Box 9.1: Nyari's Case Study**

Nyari is a 24-year old married mother of two. She lives in Mbare with her second husband. She has two children; one is from her previous marriage. She is not employed. She tested HIV positive in 2010.

Nyari has a long history of HIV testing. She says there is a time when she would test on a monthly basis. This is because she suspected that her partner (her current husband, then her boyfriend) might have been HIV infected because he had had many past sexual relationships, and his child was sick (and later died), with symptoms which she thought resembled AIDS. Despite these suspicions she had not been able to negotiate condom use with her partner. Each time she suggested condoms he would accuse her of being unfaithful, saying she wanted to use condoms because she knew she had contracted a sexually transmitted infection from somewhere and was worried about passing it on to him. *"I tried and tried (to get him to use condoms), but you know what men are like...he said maybe you are doing something outside our matrimonial home."* As a result she stopped pressuring him about the use of condoms. She would suggest HIV testing as a couple, but he would refuse.

In 2010, after a series of HIV negative results, she tested HIV positive. She reported that she was devastated, and was angry with both herself and her husband: herself for not having been firmer in demanding protected sex, her husband for not caring enough to protect her from HIV. At the time of interview she reported that she was still dealing with this bitterness. She reported that the bitterness was worsened by the fact that her husband was cheating on her with his ex-wife.

After her HIV diagnosis she immediately sought HIV care for herself; she has had regular CD4 counts since her diagnosis and she is not yet eligible for ART. Soon after her HIV diagnosis she suggested HIV testing to her husband, but he refused until he became very sick. While seeking treatment for the illness he was tested HIV positive and was initiated on TB treatment and ART.

During the in-depth interview, it was clear that Nyari valued the health of her baby; she reported that she did all she could to protect her baby from HIV; she was highly motivated to give cotrimoxazole and nevirapine prophylaxis. She attended all her prescription refill visits and reported that she always gave the medicines to the baby as instructed. *"It causes you to constantly be alert; this is a baby I love, it's a life...since the nurses who have the experience said it works so I have to make it possible."* She breast-fed her baby for two months then she stopped because she wanted to reduce the chances of infecting the baby with HIV. Six weeks after cessation of breastfeeding she took her baby for HIV testing. The results took a long time coming; she finally collected the results after the baby had turned five months old, and was devastated when she was told that the baby was HIV positive. When she was seen for her six-month visit she did not have any of the vibrancy she had had in previous visits, she looked defeated and was in a lot of emotional pain. She confided that she had even considered doing things she should not have done, possibly suicide (it was not clear what, it had not been possible to probe her because she was too distressed).

*I was hoping that she would be negative, and that one day I would tell her that I was positive, and tell her why I was taking tablets. Now I will have to do regular routines of collecting my drugs and hers also. I will have to do a double job*

She reported that she had stopped giving cotrimoxazole because she no longer believed in the health care interventions.



**Box 9.2: Tracy's Case Study**

Tracy is 29 years old. She is divorced and lives in Mbare with her three children (seven year old twins and the baby). She is HIV positive; she was diagnosed during labour when she delivered her last baby, who was five months old at the time of interview. She delivered without having registered for ANC because she could not afford the user fees; she had not known her HIV status during pregnancy. She got single dose nevirapine at delivery for prophylaxis and the baby was given a 28-day course of nevirapine. Tracy worked as a dancer; she owned the dance group she worked for. The group did performances in various towns so sometimes she was away from home for a few days. When she was away her sister looked after the baby.

Tracy was very happy that her baby was on cotrimoxazole; she believed that it was good for him, saying it protected him from childhood infections. She felt her baby was healthier than other babies in general because of this protection. Because of this she was motivated to give cotrimoxazole. She had no challenges giving it at home. She reported that there was only one time when there were adherence problems; she was out of town with her dance group and her sister forgot to give the medicine for three days. However she believed the problem had been dealt with as they introduced the use of an alarm on the phone that would help the sister remember.

Tracy had had challenges collecting cotrimoxazole for the baby from the clinic. The first time she tried to get it she was told that it was out of stock; the second time she tried to collect it the nurses told her that she was late in coming to the clinic (it was at about 3pm; the clinic closes at 430pm) and they sent her away without the medicine: *"The nurses said, 'You have deliberately come in late, today we are not providing some services, we are on a go slow.'"* A go slow is similar to a workers strike where workers withdraw some of their services in a labour protest. Such a workers' labour action had not happened at Mbare Clinic (at least during the period studied) so it was odd that a nurse had said that to Tracy. As a result of these problems Tracy had been getting her cotrimoxazole supplies from private pharmacies.

At the time of interview Tracy reported that she had a friend who worked at the clinic as a cleaner and that friend had offered to help get the cotrimoxazole for her. The friend took Tracy's national identity card and the baby's medical record and said she would use these to collect the baby's cotrimoxazole from the nurses. At the time of interview Tracy was still waiting to have the medicine delivered by her friend.

Tracy was having problems coming to terms with her HIV status. Although she had suspected that she would test HIV positive (because she had had many sexual partners), she said it was difficult to come to terms with. Her coping strategy was to try and block it out of her mind:

*I am putting effort to block it out of my mind. I heard some people say if you think about it too much, he-e-e your mind...you will get stressed and you will die quickly. So if I pretend it doesn't matter and ignore it...I block it out of my mind because I could become stressed and leave orphaned children.*

It is likely because of this failure to confront the issue of her HIV infection that she had not sought HIV care for herself. By the time of interview she had not yet sought CD4 testing; she said she kept procrastinating. Her baby had been tested for HIV (at six weeks) but she had not collected the results (even after 6 months, when her study participation ended, she had not collected the results); she said this was because there were long queues at the clinic where the results were collected, which made it difficult for her to collect the results. It is likely that her reluctance to think about the issue of HIV (stated above) also contributed to her delay in getting the results.

Tracy disclosed her HIV status to her sister and two other friends. She said it was not wise to disclose to other people in general because they would spread the information around and people would laugh about it. She reported that her landlord was HIV positive and people in her community would laugh at her. *"I have to avoid telling someone from my community because I don't know if they will keep it to themselves or if they will help me. Maybe she might go about telling everyone about it, laughing at me."*

### 9.3 INTERVIEW FINDINGS

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In the next sections I will discuss the findings of the study under the following headings: 1) Women's feelings about testing HIV positive; 2) Adherence to cotrimoxazole prophylaxis, where I will describe the adherence experiences and facilitators and barriers to adherence; 3) Other issues affecting HIV positive women including access to early infant diagnosis services and dealing with an HIV positive result for the infant, challenges with infant feeding practises and with access to women's own HIV care.

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#### 9.3.1 Feelings about testing HIV positive

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In-depth interviews revealed that women had had a deep-rooted fear of testing HIV positive which was intertwined with deep concern for their children and lack of good understanding of HIV disease and available preventive and treatment interventions. During in-depth interviews, all participants reported that they were devastated when they were told that they had HIV. They had found the diagnosis difficult to take in, and some reported that they had even contemplated suicide. Most participants said they had immediately interpreted the HIV diagnosis as warning of imminent death. This made them worry about the welfare of their children whom they thought would soon be orphaned.

*When I got home I started unpacking my bag, then I saw the tablets (ARV prophylaxis tablets) I had been given. And I thought: Is this really my status? Does this really mean I am about to die? All my thoughts were about death. Then I thought: How will my children cope? Then my head started aching and I started sweating...Maka, 24 year old married mother of two, diagnosed with HIV during the eighth month of her most recent pregnancy*

*I immediately thought about my children's ages...My oldest child is in Grade 2 (about eight years old), then there is another one who comes after her and then this one I have just delivered. My children will go through life without me, that's what I thought...Fungai, 27, year old married mother of three*

Other women worried about being stigmatised, and this will be discussed in detail in later sections.

For the majority of women the positive results had come as a terrible surprise, which participants reported made it more difficult. Lack of understanding about HIV infection and

disease had given some participants a false sense of security. They did not think they were at risk of HIV infection: some because they had had only one lifetime sex partner and some because they felt and looked very healthy. There were feelings of blame and betrayal directed at husbands who were assumed to have transmitted the infection. Husbands were blamed for not caring enough to protect their wives from HIV infection.

*What disturbed me was...where did I get it from? The person who married me gave me HIV. That is what disturbed me the most. **Barbara, 23 year old mother of one***

Fungai, a 27-year old mother of three had known that her husband, a long-distance truck driver, was having affairs because she had often found evidence (e.g. ear rings) that there had been women in his truck. She had nonetheless not expected to test HIV positive because both she and her husband looked and felt healthy and she thought he always used condoms in his extra-marital affairs:

*It (HIV diagnosis) surprised me because no part of my body ached. Plus I thought since I am this strong what problem can I have. When I looked at my husband I thought haa-a, how can we possibly have such a problem. So it shocked me that ah! ... About the ear rings, yes I had seen them, but because he was healthy I didn't think he could have it (HIV). Plus every time he went away...my grandmother told me that, "my granddaughter, men...wherever they go the first thing they look for is a woman, so if you are wise whenever you pack his clothes for travel you should put condoms in his pockets." So I would find the condoms and place them in all the pockets... And he even said to me, "A-ah, but you are a clever woman!" So I thought if he does it he will use them... I didn't think he would throw them away. **Fungai, 27 year old mother of three***

Six women reported that they had suspected they would test positive because they (one woman, Tracy) or their partners had engaged in risky sexual behaviour. They too reported that it had been devastating to be told that they were HIV positive: having suspected that they could be infected did not prepare them enough for the result. Stacy, who was diagnosed during pregnancy in 2008, reported that she had been afraid of testing because she had had a strong suspicion that she was positive as her husband was promiscuous. When her fears were confirmed she found it difficult to deal with, and had even contemplated suicide. It was the thought of her children's welfare after her death that made her discard the suicidal thoughts.

*Initially when I was tested I sneaked out without collecting the results. I did not collect them because I was scared. But because we kept coming to the ANC clinic the nurses kept encouraging us and counselling us, then I understood and I went to collect the results... When I was told that I was positive it disturbed me, but at that same time I started thinking about the children, and I thought that if I refused to accept that I was now positive and committed suicide then who would take care of my children? **Stacy, married mother of four, diagnosed in 2008***

Participants reported that their initial reaction to their HIV diagnosis was replaced by more positive thoughts over the course of time.

### **9.3.1.1 Factors Affecting Acceptance of HIV Status**

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#### *1. Support from husbands/partners*

Husbands played an important role in helping women come to terms with their HIV diagnosis: women whose husbands were supportive reported that this helped them cope better. This is particularly important because some men had specifically forbidden their wives from getting tested for HIV, while some had allowed the women to get tested on condition that they did not tell them the outcome: “*He said if you are tested don’t tell me the results, it’s your own business.*” Women were therefore in a difficult position: first they did not feel able to opt-out of HIV testing (because the environment at the clinic did not allow it, as described in Chapter 7) so they had gone ahead and tested; second, after testing HIV positive they were battling to come to terms with their HIV diagnosis while at the same time they worried about whether, and how they would disclose the HIV result to the husband who had either forbidden them from testing or from disclosing the results.

*Before I came to book for ANC I told him that at the clinic we will be required to test for HIV. So let’s go together. And he refused; he said if you are tested it’s your own business. So it was incredibly difficult for me when I eventually tested. **Stacy, married mother of four***

It was therefore a relief, and it was much appreciated, if upon disclosure, the husband responded with concern and was supportive, even among women who had initially been angry or hurt that the husband/partner had given them HIV.

*What disturbed me was...where did I get it from? The person who married me gave me HIV. That is what disturbed me the most. But with time I accepted it because when*

*I told him he received it well and we went for couple testing and he accepted it.*

***Barbara, 23 year old mother of one***

Two participants were in a discordant couple relationship; their husbands got tested after they did, and both appreciated the support they received from their HIV negative husbands. For Stacy this was a huge relief because her husband had initially been opposed to HIV testing and had himself tested only after she had put pressure on him to do so.

*I was expecting that he would start shouting at me, saying how come you have the disease, where did you get it from? But he was the one to say ahh it is possible to get a situation where the man has no disease and the woman has it...So because he did not get angry the situation did not become too difficult for me; because my husband showed me love, and said let's remain together. . **Stacy, married mother of four***

Unfortunately, out of the 20 interviewed women, 10 had husbands who did not respond so well. Some showed no interest; they ignored the result and did not do anything about it. Some took the news very lightly and chastised the women for worrying about it in the first place. Blessing's husband told her that he could not understand why she was worried because everyone in the country has HIV. "*He said HIV is now widely distributed in the whole country...there is no one who is still HIV negative.*" As described above, some men remained disinterested even when the women disclosed the results.

*My husband is the only person I told that I had been to the clinic and tested positive. And he just said alright; and it was in such a way that a-ah you are the one who was told, I am not involved, deal with it yourself. **Fungai, 27-year old married mother of three***

Some husbands dismissed the result, saying it was not true. The reasons given for not believing it included distrust of the health care workers, distrust of the test procedures or refusal to believe that a woman who looked healthy could test HIV positive.

*He refused to accept the results; he was saying: "From which area of the body was the blood drawn? How much blood was collected? These results are false; that blood is going to be sold. They lied to you; all these are lies. How can you have HIV, looking good as you do?" **Maka, 24 year old married mother of two***

It was clear that some men did not have adequate information about HIV, and this limited their ability or willingness to confront the reality of HIV infection in the family. It was also evident that men were in communication networks where mythic stories about HIV were told. Another participant, Saru, reported that all members of her husband's family were dismissive of the credibility of HIV tests. Some family members were tested HIV positive but they all do not believe the results. Ensuring that men are engaged in social or family networks where correct information on HIV is shared can help families cope with HIV diagnoses.

*...my mother-in-law died and had been diagnosed of TB. She got sick, and she came and got tested here, and the family said to the counsellor, "You are lying that our mother is HIV positive." My sister-in-law also tested HIV positive and she refused to believe the results. So when I disclosed my results he (husband) said, "All these things which are discussed in Room 15 (the main HIV testing and counselling room at Mbare Clinic) are lies. How can it be possible that you have AIDS, and my mother also had AIDS, and my father also has AIDS? How can the whole family be said to have AIDS? Saru, 36-year old married mother of two*

Although it was evident that some men genuinely knew very little about HIV, there was suggestion that this was slightly exaggerated for the participant's 'benefit'. For example, Maka believed that her husband's 'ignorant-sounding' statements were an effort to make the moment lighter for her. Because he saw how distressed she was by the result, he may have thought that by rejecting the results he would make her worry less about the diagnosis. However this did not work, it added to her worries, as was the case with all women who reported that their husbands had refused to engage in meaningful discussions about HIV. It could have been the man's strategy to avoid dealing with the reality of HIV in the family; because they had rejected the results they could not be expected to hold meaningful discussions about HIV with their wives. As will be seen later the men may have used this to protect themselves from acknowledging that they may also have HIV; they could then keep their HIV status ambiguous. This not only left the woman without support to deal with her new HIV diagnosis, but affected medication adherence as well, and this will be discussed in the next sections.

## 2. Counselling and education

Women's poor understanding of HIV issues made the HIV diagnosis more frightening than it should have been. Some women worried that they were about to die, while some did not

understand that it was possible to give birth to an HIV negative baby. Participants reported that they felt better after they had received they got counselling and education about HIV, particularly when some of the untruths they knew about HIV were addressed. Five women, who reported that they had felt hopeless soon after being diagnosed HIV positive, said they felt better after talking to the study nurse; the study nurse counselled and educated them in response to their concerns and questions.

*When I got home I cried, and I thought: what will become of me now that I have the disease? What if I just die, what difference will it make...is it not better than waiting until I am seriously ill, when people will be pointing at me, saying look what she has become? What if I just take rat poison? I got to that point. Then I spoke to Sister T (study nurse) and she explained to me that if you have the disease it does not mean that you are different from someone else who is walking next to you, you are just the same. If you have the disease it does not mean that the diagnosis is stamped on your forehead...Your life does not stop just because you have been told that you have HIV. That's when I realised that ah, really, that's the way it is. And for sure up to now I know that even if I have the virus in me I can survive. **Fungai, 27, year old married mother of three***

*I was really troubled until I met people who counselled me until I understood. I would ask Sister T (study nurse) how to proceed given my situation. **Maka, 24 year old married mother of two***

Another participant, Barbara, sought counselling and support from a social support centre where she had been referred by the clinic nurses:

*She (the counsellor) helped me to accept it as it is...she told me that I can give birth to a normal baby who can grow up without HIV. Because I have mostly worried about the baby, what would become of it ... But she (the counsellor) was able to help me by assuring me that it is possible to have a negative baby. That is what helped me.*

**Barbara, 23 year old mother of one**

Of note, in all cases the education and counselling that participants reported made them feel better did not come from the clinic nurses, but from other sources. Because the clinic is busy, clinic nurses may not have had time to spend with women and check understanding of HIV issues; many women came out of the clinic counselling session with unanswered (and

unasked) questions which made the period soon after HIV diagnosis difficult. One participant actually mentioned that the post-test counselling session had been very brief:

*They did not really say much because it was just ANC registration, and there were also many people. One would just speak briefly that (imitates a nurse using a prescriptive voice, also sounding like a recital),*

*“You have been found to have the disease,*

*The baby will breastfeed for six months,*

*Unless you have money and you are able to buy formula milk...”*

***Fungai, 27, year old married mother of three***

Other participants said they had found the support and encouragement from family very helpful. The most common support that family/relatives gave was that the woman should not feel bad because she was not the first one to test HIV positive, there were many other people living with HIV. Indeed participants themselves reported that there was comfort in knowing that they were not alone in their situation. They felt particularly encouraged if the HIV positive people they knew were doing well; which they reported inspired them to follow in their footsteps in terms of health-seeking behaviour.

*Ahh I am no longer worried. I just comfort myself with the thought that how come this person is surviving, how come this other person is surviving. My mother is living with HIV; she was diagnosed in 2009 and she is taking ARVs. Even my sister-in-law, my husband’s sister, she was diagnosed when...the baby she delivered soon after diagnosis is now seven years old. Sekai, 35 year old married mother of two*

### 3. Belief in the ‘inevitability’ of HIV infection

About a third of women reported that they felt better when they adopted the belief that HIV was a part of life that could not be avoided. The women thought of it as “an inevitable occurrence/disease that had come to humankind so there was no point in stressing over it”. Religious beliefs played a part in the generation of this view: some women felt that God had allowed it to happen and they were powerless to avoid it. “*There is nothing you can do; it is the will of God.*” There was belief that God would provide the solution to the problem and would protect the participant and her family in the same way that he had already protected other people living with HIV.



#### 4. Time

There was evidence that women who have known their HIV status for a long time were doing better; they were evidently more comfortable with their HIV status than women who have recently diagnosed. This might have been because they had time to adjust to the status and gained more confidence that they could survive, and may have been encouraged by witnessing their own survival. Three women, Mucha, Vongai and Tendai, who tested HIV positive in 2005, 2007 and 2008 respectively, were so comfortable that they sometimes provided HIV counselling to other people in their communities, particularly testifying of the importance of seeking health care to those people who were afraid of testing for HIV.

#### **Women who did not have support to deal with their HIV status**

The role of all the above factors in enabling acceptance of HIV status is further evidenced by the fact that three women who did not have any support and did not have any of the above factors to their advantage were evidently still struggling to cope with news of their HIV status at the time the interviews were held. One such participant, Tracy, decided that trying to come to terms with her HIV status was too painful, so her coping strategy was to block it out of her mind. As will be discussed later in this chapter, this can have a negative impact on health-seeking behaviour.

*I am putting effort to block it out of my mind. I heard some people say if you think about it too much, he-e-e your mind...you will get stressed and you will die quickly. So if I pretend it doesn't matter and ignore it...I block it out of my mind because I could become stressed and leave orphaned children. **Tracy, 29-year old divorced mother of three***

Another participant, Nyari, did not believe in the inevitability of HIV infection; she had suspected that her husband (then her boyfriend) had HIV because his child was sick with what she thought were signs of AIDS. At the time she regularly tested HIV negative, she asked him to get tested and he refused, and when she tried to get him to use condoms he had also refused. This participant was having problems coming to terms with her diagnosis because she could not stop blaming her husband for infecting her, and she also blamed herself for not being firmer in demanding protected sex.

*I was angry because when we were boyfriend and girlfriend he refused to get tested when I asked him to. I was angry that the person I was with had not paid attention to what I was saying, which had caused me to eventually test HIV positive. Then I*

*blamed myself because I had neglected to put that pressure on myself...I should have insisted that what I have said goes, without that we cannot go on...*

This section describes the difficulty that HIV positive women face at time of diagnosis and highlights the inadequacy of the post-test counselling session given by nurses in helping women deal with their HIV status. Husbands/male partners are shown to significantly impact the responses of women to the new status: supportive men make it easier, but unsupportive men actually make it worse. While women adjusted to their HIV status they had to give cotrimoxazole to the babies and I will now describe their experiences with this.

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### **9.3.2 Adherence to cotrimoxazole prophylaxis for babies**

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All women reported being able to give cotrimoxazole on a daily basis without forgetting; in fact many were emphatic that they did not forget to give cotrimoxazole because they valued the health of the baby. However some women experienced some adherence challenges which were beyond their control and these will be discussed later in this section.

During home assessment of adherence visits women generally confidently measured out the cotrimoxazole, showing familiarity with the procedure. However a problem was noted with dosage: among twelve participants for whom home assessments were successfully completed, only five accurately measured the prescribed amount (within 0.2mls of the prescribed 2.5mls). (The reasons why only 12 of 20 women had successful home visits will be given in the section on barriers to adherence). Four women measured less than the required amounts: 1.1, 1.3, 2.1 and 2.0mls each. Two exceeded the prescribed amounts with measures of 3.5 and 4.2mls. Participants were instructed by nurses to give 2.5mls or half a teaspoonful. Four of the participants with inaccurate measurements used teaspoons, but the capacities of the teaspoons were not 5ml, hence the inaccuracy. One participant used a small measuring device which she believed measured 2.5mls, but in actual fact it had a capacity of 2.0mls. The participant who measured 4.2mls, Stacy, reported that she had been told to give 5mls; however her medical record indicated 2.5mls, so there had been a misunderstanding. Barbara had had a similar problem; during the monthly visits, before the home visit, study staff discovered that she was giving a quarter teaspoonful because that is what she understood she should give. Study staff told her the correct dosage, and when the home assessment was done she measured the correct amount of 2.5mls.

### 9.3.2.1 Facilitators to adherence

#### **1. Desire to ensure the good health of the baby**

Participants valued the health of their babies above all else. They all reported a strong willingness to give cotrimoxazole prophylaxis in order to preserve the health of their babies. Of note, among fourteen participants in which this was explored in detail, eight women believed that cotrimoxazole protected the baby from acquiring HIV through breast milk. Five were aware of its role in protecting against infections in general, and not HIV, and there was one woman who thought it protected against many infections including HIV. *“It prevents the baby from getting chest infections, and then it prevents the baby from getting HIV from the mother.”* The difference in knowledge of the purpose of cotrimoxazole seemed not to be associated with a difference in attitude towards cotrimoxazole; all participants valued it highly and attached great importance to adherence. As mentioned above the desire to keep the baby healthy ensured that participants did not forget to give the medicine:

*It causes you to constantly be alert; this is a baby I love, it's a life...since the nurses who have the experience said it works so I have to make it possible. Nyari, 24-year old married mother of two*

*What encourages me to adhere is the desire to prevent my baby from becoming HIV positive. That's what encourages me mostly. I am really concerned about my baby. Barbara, 23-year old married mother of one*

#### **2. Observed benefits of using cotrimoxazole prophylaxis**

Many participants reported that they had experienced the positive effects of cotrimoxazole prophylaxis. They felt that their babies were healthier than other HIV-exposed babies who were not on medication. Women who had previous children who had not been on cotrimoxazole marvelled at how much healthier the new babies were compared to their older HIV exposed (or positive) siblings. The perceived benefits of cotrimoxazole encouraged the women to keep giving cotrimoxazole.

*Since the time I gave birth I have noticed that giving cotrimoxazole to the baby is helpful. If you keep giving cotrimoxazole every time he does not suffer from colds, or diarrhoea like what other children do. A baby who gets it is really different from the baby who is not taking any medication. Tendai, 27-year old married mother of four*

*Cotrimoxazole is important because in the community I live there are some children who are not on medication, as I speak right now they have been to hospital a countless number of times. But with this child I have not been to hospital since delivery. Stacy, 35 year old, married mother of four, thinks cotrimoxazole is important for PMTCT*

Having a baby test HIV negative at six weeks was reported to provide encouragement and further impetus to keep giving cotrimoxazole. This was likely because of increased confidence in the health care interventions that were offered at the clinic.

*When I was given her HIV test results (tested at six weeks) that's when I became more convinced that it is important to adhere to the given instructions. Nyari, 24 year old married mother of two*

Unfortunately, the converse was also true for Nyari. She had been encouraged to adhere to cotrimoxazole when her baby tested HIV negative at six weeks, but she was discouraged and she stopped giving cotrimoxazole when her baby later (about a month after the in-depth interview) tested HIV positive. She reported that she had lost faith in the drugs and could not bring herself to give cotrimoxazole again. When she was seen at the six-month visit, she had not given cotrimoxazole for about three weeks. This is especially concerning because it is the HIV positive baby who needs cotrimoxazole the most. This unfortunate experience could be one of the adverse effects of believing that cotrimoxazole prophylaxis has PMTCT properties.

### **3. Aids to remembering**

In general, many of the women were strongly motivated to administer cotrimoxazole and they took significant steps to remember to give it on time. Women reported that they used their phone alarms as aids to remembering. Also, women reported that they had already established their routines of taking medicines (antiretroviral drugs, cotrimoxazole prophylaxis and ARV prophylaxis) and it was easy to fit the babies into these routines.

### **4. Social support for adherence**

Family members who were aware of the need for cotrimoxazole prophylaxis were reported to be supportive for adherence mainly through giving reminders. Some husbands were reported to be supportive, as will be described below. Of note, many women reported that their other children were often actively involved in medication adherence, some had been trained to give

the medicines, and some played the role of reminding the mother that it was time for giving the medication.

As stated at the beginning of this section, some women experienced barriers to adherence; these will now be discussed.

### **9.3.2.2 Barriers to adherence**

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The main challenges faced by women in their efforts to keep the babies on cotrimoxazole prophylaxis were 1) challenges posed by husbands/male partners, 2) fear of HIV disclosure and stigma and 3) health system challenges including stock-outs of cotrimoxazole and long queues at the clinic. These challenges will be discussed in turn.

#### **Husbands/male partners as barriers to adherence**

As stated already for some women there was a challenge with getting men engaged in HIV issues. One problem with this non-engagement is that it affected medication adherence. Of note, there appeared to be a striking ‘dose-response’ relationship between the level of engagement in HIV issues and support for adherence: the less engaged a man was the less supportive for adherence to cotrimoxazole he was. Three groups of men were identified: 1) the group that provided the most support for adherence, 2) the group that was not opposed to cotrimoxazole but did not actively support it, and 3) the group that was opposed to cotrimoxazole prophylaxis. First I will describe the group that provided most support for adherence. Men who were in regular HIV care i.e. those who were on ART and those who were not yet eligible for ART but were in regular follow-up at HIV clinics were the most supportive: they accompanied their wives to consultation visits, and they took an active part in ensuring that the baby was given cotrimoxazole at home, e.g. by reminding the woman to give cotrimoxazole, and by buying it from the pharmacies in the event that it was out-of-stock at the clinic. Out of 16 married women, only six had such husbands.

The next group consists of five men who had taken some steps towards confronting HIV issues. All initially had negative reactions when the women disclosed their HIV results but with time they came to a point where they could discuss their family’s HIV care; they accepted the wife’s HIV status and were not opposed to the baby taking cotrimoxazole, although they did not actively support it. They allowed the wives to give cotrimoxazole as instructed by health care workers. Their main challenge was that they were not ready to share their own HIV status with their wives. All of them refused to go for couple counselling and

testing, and two of them were believed to be lying about their testing histories. Tari believed that her husband had not yet been tested although he had told her that on two separate occasions after her HIV diagnosis he had gone for HIV testing alone, and had tested negative. When she suggested couple testing he refused and was angry that she had suggested it. Another participant, Sekai, believed that her husband had already tested HIV positive, but he did not admit to this and instead told her that he had not yet been tested. There was suggestion that the response to HIV was shaped by relationship dynamics and gender norms. It appeared that men felt HIV stripped them of their masculinity; it was more acceptable for the woman to have HIV than the man. None of the five men were ready to admit their vulnerability to HIV to their wives. One of the women, Maka, reported her husband, was scared of HIV testing: *“He is afraid that if he tests positive I might leave him.”* Since he did not leave her when she tested positive, this provides support to the notion that men felt emasculated by HIV and did not want their women to view them in this way in case they thought less of them than men who did not have HIV. Another man from the least supportive group, Saru’s husband, provided further support to this view. When his wife told him about her HIV status *“he said a-ah that’s the business of women. I myself will never get tested for HIV.”*

The least supportive group were opposed to cotrimoxazole prophylaxis for the babies. The group consisted of husbands of five participants: Grace, Saru, Ruth, Fungai and Miriam. They were reported to have told the women that they did not want to know their HIV status. When their wives told them their results they refused to accept them and refused to understand the reasons why the baby had to be on cotrimoxazole. Three of the men forced their wives (Grace, Saru and Ruth) to stop giving cotrimoxazole to the babies.

*I explained that the cotrimoxazole is for prevention of infections. And he said ha-a my child is not going to keep taking medicines willy-nilly. **Grace, 23-year old married mother of two***

Ruth’s husband told her to stop giving cotrimoxazole because he felt it could harm the baby. Their first child who died and some of his relatives are reported to have had adverse reactions to cotrimoxazole and he wanted to avoid that happening to the baby. It was not clear how genuine this concern was because he would steal Ruth’s cotrimoxazole to take himself. The baby had been on cotrimoxazole for about two months and had not reacted to it, so Ruth did not understand his concern. She had continued to give it in secret but when he discovered *“He said if I kept giving cotrimoxazole he would take the baby away from me and give him to*

*his mother.*” Her mother-in-law also stepped in, telling her that cotrimoxazole prophylaxis was not worth fighting over or losing her marriage over, so Ruth gave in and stopped administering cotrimoxazole.

Grace and Saru were taking cotrimoxazole for their own HIV care, and the husbands stopped them taking it as well.

*About a month after I delivered he suddenly asked me what the tablets (cotrimoxazole) were for. I explained to him and he became angry and said, “This is madness, these are all lies.” Then he took the tablets and threw them away.”* **Grace, 23-year old married mother of two**

Grace’s husband also threw away hers and the baby’s handheld medical records. The men’s behaviour may be explained by the fact that they did not want to know their own HIV status; they were not able to deal with the possibility of being HIV infected because they felt that their masculinity would be threatened, as suggested by Saru’s husband. That their wives had tested HIV positive might have been indication to them that they were likely to also test HIV positive, and they did not want to face that. Neither could they face continued confrontation with the reality of HIV infection in the family in wives/children who were taking daily HIV medicines, hence the move to stop the women from giving/taking the medicines. This view is supported by Miriam’s situation: she reported that her husband did not receive news of her HIV diagnosis well. He is reported to have been so disturbed by the results that she described him as “unstable”. He no longer said much. *“He has lost weight and has lost his appetite.”* Because of this she did not think he was strong enough to receive news that the baby was taking cotrimoxazole prophylaxis, so she did not tell him. She thought that if he found out it would push him over the edge because he would assume it meant that the baby was sick. She worried that he would then leave them. *“If I tell him that the baby is taking some medicine he will start thinking too many things. He might leave us forever because he will think that a-ah this child is sick with HIV.”*

These data suggest that some men (possibly those not exposed to HIV testing and counselling) are unable to cope with HIV diagnosis. Their response not only delays their own testing but threatens the health of their partners and children by stopping their access to medicines. Public health campaigns have tried to educate men about HIV, and to encourage them to go for counselling and testing. Those men who had been counselled and tested for HIV did not have negative attitudes to HIV and even had positive health-seeking behaviours.

The six husbands who were in regular HIV care and had been to couple counselling sessions provide evidence for this. Sadly, three of them had only sought care as a result of either themselves or their child being seriously ill. Of importance, however, is the role of women: Stacy's husband (one of the group of more supportive men) and Maka's husband (in the second group) initially had very negative views about HIV testing and counselling but they changed after the wives' interventions. The wives continued to put pressure on the men to confront the issue of HIV. Stacy reported that she refused to have unprotected sex with her husband, insisting that he should first get tested for HIV. He resisted this, saying he was "not going to use a condom with a woman he had paid lobola for" but she remained firm. He eventually gave in and went for testing. Afterwards they both went for couple testing and he has been very loving and supportive despite him testing HIV negative. Maka's husband also got some pressure to start confronting HIV issues from his wife: she refused to talk to him until he promised to start working towards confronting the issue of HIV in the family. He was reported to have changed his attitude considerably, from the initial attitude where he did not believe her HIV test result to one where he believed the result and was promising to soon get tested himself. Women therefore have a critical role in supporting the health seeking behaviour of their husbands, although the capacity they have to intervene is significantly influenced by their relationship circumstances i.e. risk of violence or having the child taken away, as in Ruth's case.

Marital strife may also result in adherence challenges; a look at Fungai's situation illustrates this. Fungai is the woman who would pack condoms for her husband. He openly conducted extra-marital affairs, and he also stole her cotrimoxazole tablets to take himself. The latest disruption was when he brought his mistress home and spent the night with her on their marital bed while Fungai was made to sleep on the floor, in the same room. After this incident Fungai left her husband and went to the rural areas, but because of her distress when she left, she forgot to take the baby's medicine. So her baby did not take cotrimoxazole for a few days. While in the rural areas she found someone who said she used to give cotrimoxazole prophylaxis to her child, and had some left-over cotrimoxazole; she got that and started giving it to her baby. This illustrates that she recognises the importance of the baby taking cotrimoxazole and will do anything to ensure that it happens. It is obviously not ideal; one would hope that the medicine she got was indeed cotrimoxazole, that it was not expired or that it had been kept in good enough conditions to still be suitable for giving to the baby. Her case, like that of a significant proportion of women in this sample, illustrates that



they have significant motivation to adhere but their capacity to implement is shaped by their circumstances and relationships.

### **Fear of HIV disclosure as a barrier to adherence**

The fear of HIV disclosure presented challenges to participants both for giving cotrimoxazole at home and for collecting prescription refills from the clinic. Women felt that the community generally does not have good understanding of HIV, and does not have a positive attitude towards HIV positive people. People in the community were reported to laugh at or ridicule HIV positive individuals and to refuse to associate with them. Women were therefore keen to prevent unwanted HIV disclosure in order to avoid these stigmatising attitudes. This resulted in some participants giving us the wrong physical addresses for where they lived because they feared that the home visits would result in HIV disclosure. This was the main reason why there were low numbers of completed home visits. Rumbi gave a false address; during the in-depth interview she said she was worried about disclosure of her HIV status to her father and step-mother whom she reported had poor understanding of HIV. *I have not told them because I worry that they will look down upon me and they will no longer want me to live with them because they will think I will spread the infection to everyone who lives in the house.* In two cases participants were visited at home but the study procedures could not be done because there were other people around in the house/room.

A recurring theme among participants was the fact that stigmatisation results in increased stress levels which would lead to earlier death. All women who reported that they were worried about HIV disclosure and associated stigma said they knew of other people living with HIV who were being laughed at, looked down upon or discriminated against. This was particularly challenging given the crowded accommodation that the women lived in; they hated the fact that people could discuss and laugh at someone who was known to be HIV infected in the shared spaces like bathrooms and corridors where a lot of people would hear. This gossip was believed to have an adverse effect on the health of HIV positive people, which participants were understandably keen to avoid.

*There is one woman who is on HIV drugs who people always talk about; because of that her health never improves, she is always sick. She chose to share her HIV status with everyone but now people just go about spreading word that she is taking HIV medicines and the like. She is always sickly. **Tendai, 27-year old married mother of four***

There was limited voluntary disclosure of HIV status; the women generally told their husbands and one other person, but there were four women who had disclosed only to their husbands. It was common for participants not to have disclosed to other people living in the same household e.g. sisters and other relatives they lived with. This presented a challenge with giving the medicine especially given that participants generally lived with many family members in a single room. Maka, who earned a living through street vending of meat, said she worried that if people knew her HIV status they would stop buying her meat because they would think it was infected with HIV. She lived with her sister whom she did not trust enough to disclose to because she was likely to “spread the information around.” Maka reported that she did not give the cotrimoxazole in sister’s presence; she would wait until the sister left to go to the market before giving medicine to the baby. Interestingly, she reported that before she tested HIV positive she used to have the same attitudes towards people living with HIV because she was afraid of being infected by them. She found it hard to accept groceries from a cousin who she knew to be HIV infected. *“I would only accept groceries which came in sealed packages like rice or sugar. If he gave me some meat I would worry that he might have cut himself and infected the meat...”* HIV stigma was therefore a reality that participants had experience with, having seen it being directed at other people, even by themselves. They knew the extent of its ugliness and did not want to be recipients of it.

Another participant, Barbara, reported that if there were other people in the room when it was time to give the medicines she would pretend to go the toilet, and she would give the cotrimoxazole to the baby there. *“The challenge is people can come before I have given the medicine; then I will take the bottle outside... I can actually go and give the medicine in the toilet”*. This not only highlights the constraints in giving the medicine when there is fear of HIV disclosure but also highlights the potential hygiene issues given the uncleanness of the shared toilets.

The other reason why women wanted to keep their HIV status unknown to the general public was to protect their children. Women desperately wanted to shelter their children from the ‘cruel’ world; they did not want them to be subject to any stigmatising attitudes.

*I don’t want people to find out themselves because they will assume that my baby is HIV positive. Then they will no longer want to hold my baby...I would like an opportunity to clearly explain everything to them, that I got the baby treated and she does not have HIV. Barbara, 23-year old married mother of one*

It was also common for women not to have disclosed their HIV status to their other (older) children. All the women who had not told their children reported that they did not feel the children were mature enough to handle the information, so they worried that if people talked about their HIV statuses in the common/shared spaces the children would hear them and they would be adversely affected.

*“We live with small children whom we are not yet able to hold these discussions with because they don’t understand. So if they find out through someone else they might not be able to handle it, they will think that a-ah my mum is about to die and they will be distressed, yet they are such small children.”* **Tendai, 27-year old married mother of four**

Just as an aside, it was noted that older children of the women must have been facing difficulties themselves. In many cases they were closely involved with the baby’s adherence to medicines; in some cases they reminded the mother to give the medicine and in others they gave it themselves but without having been formally told why the baby was taking the medicine. They knew that they were supposed to be secretive about the issue, which may have caused them to worry. Some women reported that they suspected that some of the children were aware, but they did not feel able to ask. This is what Tendai said about her 12-year old step-daughter:

*“I didn’t tell her but she seems to understand the situation. Let’s say I am doing my laundry in the evening at around seven she will tell the smaller child to come and whisper in my ear that it’s time for taking the medicines...Even when there are people in the room, she will say, “Mum, come here.” Then I will go. Then she will say, “What about today?”; then I know and will take the tablets.”*

The fear of HIV disclosure also acted as a barrier to the collection of prescription refills at Mbare Clinic. As described previously, there is a chronic diseases clinic where all patients with chronic disease attend for prescription refills. Despite the inclusion of patients with various types of illness the community views the clinic as a clinic for people living with HIV. Some participants reported that they found it difficult to collect their drugs because they feared HIV disclosure in the event that they were seen at the clinic by someone who knew them.

*Sometimes it's hard for me to collect the medicine because I might see someone I know; then it becomes incredibly difficult because I have not disclosed to anyone except my husband. **Barbara, 23-year old married mother of one***

Women who lived in an area of Mbare called Matapi were told by nurses to transfer to Matapi Clinic, another City of Harare primary care clinic, where they were to collect prescription refills because that clinic was closer to where they lived. (This process was not systematically done however; many women who lived in the Matapi area were not transferred). Four participants were transferred to Matapi Clinic; two of them went without problems but the other two were not happy with the transfer. They complained that Matapi Clinic was too close to their place of residence, so they feared HIV disclosure. Attending Matapi clinic was reported to have a higher risk of disclosure than Mbare Clinic in that it had separate queues for 1) general patients, 2) TB patients and 3) HIV positive patients.

*“Our block of flats faces the clinic, and people know what kind of patients are in each queue. If a person sees you in that queue she will rush to tell everyone in the flat, so I don't feel free to go to Matapi.”*

This participant, Tendai, reported after the interview that she was planning to lie to the nurses, telling them that she had relocated to another area that was within the Mbare Clinic catchment area. She was warned about the dangers of giving a false address to the nurses and in the end she took up the transfer to Matapi. So profound is Tendai's fear of collecting drugs from Matapi that she refused transfer for antiretroviral drug prescriptions from Harare Hospital to Matapi. From her meagre earnings she sacrifices to pay the extra transport and attendance fees in order to avoid collecting her drugs from Matapi. Matapi clinic only asks for \$1 per visit, but Harare Hospital charge \$5 and she has to have busfare as well. This illustrates the significance of the fear of unwanted HIV disclosure and associated stigma, showing that the environment that women lived in was profoundly unsupportive of HIV positive individuals. It also illustrates how difficult it is to conceal one's HIV positive status when living in a crowded environment where everybody minds other people's business.

#### **Health system barriers to adherence to cotrimoxazole**

The main health systems challenges to adherence experienced at Mbare Clinic were stock-outs of cotrimoxazole, long queues at the clinic, and the fact that at times nurses did not dispense enough cotrimoxazole supplies to last until the next appointment.

### Stock-outs of cotrimoxazole

As reported in Chapter 4, there were several stock-outs of cotrimoxazole over the course of the study. Nine of the twenty interviewed women were affected by stock-outs. The stock-outs meant that women had to buy cotrimoxazole from private pharmacies. Consequently, some babies did not take cotrimoxazole for several days because the mothers could not afford to buy it. For example, at six weeks Maka's baby was not given cotrimoxazole because it was out-of-stock. She was told to go and buy from the pharmacy. However she had no money, so her baby did not take cotrimoxazole for the next two weeks. Another participant, Mucha, was told at her six-week visit that cotrimoxazole stocks (which previously had been out-of-stock) had been received but they had not yet entered into stock cards. She was told to return to the clinic on the next day, but she did not come back for three weeks, and the baby was not taking any medicine during that time. Sometimes the stock-outs forced women to look for alternative informal sources of cotrimoxazole, which may potentially be harmful: Sekai reported that she had a friend who worked at a clinic in the rural areas and she asked her to get some cotrimoxazole for her because she could not afford to buy from the pharmacy.

Another problem was with expired drug, which was reported by one participant, Saru. After one prescription refill visit she discovered that the medicine was expired and she did not know what to do. She did not give cotrimoxazole for a few days before she came back to ask the nurses about it.

### Long queues at the clinic

Another challenge with prescription refills were long queues at the clinic. Participants reported that they typically had to dedicate the whole day to a clinic visit, which they found difficult.

*We just know that a clinic appointment means that you will spend the whole day at the clinic; you will not even have time to wash the baby's diapers. Like today I started making preparations to come to the clinic at 6am because I wanted to be one of the first ones to get help. We got here, we don't know what the problem was; they only started helping us at 10. Yet I just left the house without eating anything. I am hungry and the baby is also hungry."* **Mucha, 41 year old married mother of 5**

The problem of long queues particularly affected self-employed women who reported that it was difficult to sacrifice the whole day. They reported that it was especially disheartening when after waiting for a long time they were told that the cotrimoxazole was out-of stock.

Tracy, a dancer, reported that she found it difficult to spend a long time at the clinic, and each time she tried to get cotrimoxazole she found that it was out-of-stock, so she made an arrangement with a friend of hers, a cleaner at the clinic, who in turn told her that she had a friend who was a nurse who could get the cotrimoxazole for her. This was indication of unsafe prescribing practises, and could also be an indication of some drug pilferage at the clinic.

The other challenge related to this is that women were scheduled to attend the clinic at different times for appointments for their own HIV care and for their baby's, which meant spending more days at the clinic.

#### Disparity between next appointment date and amount of cotrimoxazole dispensed

Several participants reported that one challenge they faced when they first started collecting cotrimoxazole was that nurses did not give them enough cotrimoxazole to last until the next appointment. All of them reported that the nurses would give them an appointment date that was two months away, but only give them 100mls of cotrimoxazole, which was 40-days' supply. As discussed in chapter 6, women found it difficult to seek clarification from nurses if there was something they did not understand. As a result, when the medicine ran out before the appointment date, they started worrying about the nurses' reaction if they turned up before the appointment date that was written on the medical record, and started thinking about what explanations they would give in the event that the nurses asked them why they had come earlier than scheduled. The women reported that they had to "psyche up" for the encounter, and they were "relieved" when nurses supplied the cotrimoxazole without asking questions.

Women reported that as time progressed they no longer worried about it because they found that nurses would supply the cotrimoxazole without asking questions. It is reassuring that nurses provided refills without question, but it caused considerable anguish to women who already had many other issues they were dealing with in their lives. Women who were unable to summon the courage to face the nurses for early drug refill often reported poor adherence. Mucha reported that before she knew that the nurses would help she would give less cotrimoxazole so that it would last until the next appointment:

*I stopped giving cotrimoxazole at that time. I could not give it as directed because I wanted it to last until the next appointed date. But now I know that a-ah! I will keep going back to*

*them, nagging them, telling them that I want the baby's medicine. Mucha, 41 year old divorced mother of five*

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### 9.3.3 Other issues affecting the study participants

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#### 9.3.3.1 Early infant diagnosis

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Early infant diagnosis was offered at the Mbare Clinic at the six-week visit. Most participants had their babies tested for HIV at the six-week visit using DNA PCR on dried blood spots. However there were challenges getting the results back; a few were able to get them at the 3-month visit but some had not obtained the baby's results by the 5-month visit. Several women would complain to study staff that they were having challenges obtaining their results; the nurses kept telling them to come back later. Study staff enquired with the Sister-in-charge, and she confirmed that they indeed were having challenges getting the results back from BRIDH hospital. She said because of manpower issues the hospital required someone to come to the clinic and make photocopies of the results. The clinic was also short-staffed and found it difficult to release someone to go and make the copies at BRIDH.

The other challenge with collecting the results is that the nurses were busy, and they confided to the study nurse that sometimes they did not have the time to go through folders to look for individual results for the babies. In some cases the nurses gave the study nurse the results folder and asked her to pull out the results for the study participants. Nurses found it acceptable to ask the study nurse to do this because she was familiar; she had worked with them within the same system in her previous job. This also shows the 'better' care that the participants had because they were in the study, which is unlikely to continue once the study is finished.

#### Babies who tested HIV positive

Tracy, Maka and Tendai had HIV positive babies. Tracy and Maka's youngest babies had recently tested HIV positive. With Tendai, the youngest baby was HIV negative and she had a three year old son who tested positive at about 18 months of age. Maka and Tendai's babies were already on ART. Tracy had recently received the results when she was seen at the clinic for the six-month visit; she was still to go back to the hospital for ART initiation.

All three participants reported that they were devastated when they were told that their babies had HIV. They said they could handle their own infection, but it was just too painful to be told that the baby had HIV. Tracy was seen at the six-month study visit about three weeks

after she got results that the baby was HIV positive. Throughout her study participation, she had looked vibrant and was confident that because of the PMTCT efforts she was putting in, her baby was going to test HIV negative. She had her baby tested at Harare Hospital at six weeks, and when she was told at three months that the baby was negative she decided to stop breastfeeding, and was told to come back for another test six weeks after cessation of breastfeeding. This was the test that was positive. When she was seen for her six-month visit she did not have any of the vibrancy she had had in previous visits, she looked defeated and was in a lot of emotional pain. She confided that she had even considered doing things she should not have done, possibly suicide (it was not clear what since it had not been possible to probe her because she was too distressed), and she was grateful that her husband had been there for her and had supported her.

*I was hoping that she would be negative, and that one day I would tell her that I was positive, and tell her why I was taking tablets. Now I will have to do regular routines of collecting my drugs and hers also. I will have to do a double job. ...I thank God for my husband who was there for me. He is the one who restricted me.*

Maka reported that she also had a terrible blow when her baby's results were disclosed. She has however felt better over time because at the hospital where she collects the baby's ART she has seen some grown children who were born with HIV, and she was encouraged because they are healthy.

*I-i-i-i! The baby's HIV positive results were more painful (than mine), so it was like...I felt my hair rising above my head...It really affected me. It would have been much better if it was just me. But then again I saw other children who come to collect their medicines; some are grown up girls, actually grown women who are in universities. They said were they were born like that. So it made me feel better, and I thought ha-a, what I can I do I just have to deal with the situation.*

Despite this hope for their survival with HIV, at the end of her in-depth interview Tendai pleaded with researchers to find a cure for HIV.

*We are crying out to the researchers to find a cure for HIV. That's what we are asking. Even if it means that one will take the course for one year, it will be alright because you will be cured. That's what we are crying for, especially for the children. Even if we adults remain with the disease, but if the children are ok, it will be much better. If there was a cure for the babies I will keep taking my tablets with the hope*



*that I will live to see my cured child, it will be better. That's our request, may those who are searching please find us medicines that cure.*

As has been described in previous sections the women care deeply about their children and will do all they can to ensure the children's wellbeing, although their capacity to ensure that the child receives treatment is undermined by the circumstances in which they are living. Having a baby test HIV positive caused grief among the women, which underlies the importance of improving the quality of PMTCT services provided in order to eliminate mother-to-child transmission of HIV.

### **9.3.3.2 HIV care for the women**

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Out of twenty interviewed women, thirteen had received satisfactory HIV care by the time of the in-depth interview. Four were already on ART (these are women who had been diagnosed before the last pregnancy; they were already on ART when they got pregnant). Two women who were diagnosed during pregnancy had already taken all the required steps for ART initiation: they were eligible for ART, and they had taken the necessary medication adherence lessons, and had been given appointments for when they would be started on ART.

The other seven women reported that they had not yet taken steps towards their HIV care. They had all been referred to BRIDH hospital, the hospital that has an HIV clinic where ART initiation is done. However five of them had not yet gone by the time of interview because they could not afford the consultation fee of \$6. This presented a problem in that some women were already in need of HIV care, for example Maggie had had a POC CD4 count at Mbare clinic and her CD4 count was 230. She was thus eligible for ART initiation when she delivered her baby but by the five-month visit she still had not gone to BRIDH hospital because she could not afford the \$6. Fortunately this problem has been dealt with because the hospital is no longer charging the consultation fee. Grace and Saru (the women whose husbands were strongly against HIV care) were in this group as well. Their husbands may also have played a role in this delayed health-seeking.

The other two women who had not yet sought HIV care were Vimbai and Tracy. Vimbai reported that she did not have time to go to BRIDH. She was a widow and sole breadwinner and she reported that it was difficult to take time off her vending business to go to the clinic. She had already taken some time off when her baby was hospitalised, and the effect of this was that she failed to pay her rent, which forced her to move in with her mother.

Tracy did not report any particular reason for not having gone to BRIDH hospital. She is the woman who reported that she actively tried not to think about HIV. She said it was difficult to confront the issue of her HIV status, and seemed to be slow in all her health-seeking. For example, at about 4 months the nurses at the child health clinic told her that her baby was supposed to be on nevirapine prophylaxis, but she did not go to the chronic diseases clinic to collect it. In addition, although there generally were problems with obtaining the baby's HIV results, she did not seem to be putting as much effort as the other women to get them. She did not want to join the queues at the chronic diseases clinic; she is the participant who made arrangements to get cotrimoxazole through the cleaner. This suggests that denial of HIV or disengagement in HIV issues may adversely affect health-seeking behaviour. This was also observed among men who refused to confront HIV issues in their families.

### 9.3.3.3 Challenges with infant feeding practises

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Another challenge that women faced in caring for their babies was related to feeding methods: women were taught about the benefits of exclusive breastfeeding and instructed to practise it for the first six months of the baby's life. Some women reported that exclusive breastfeeding was hard; they felt that the babies were hungry and the breast milk was not sufficient for them. The cultural beliefs in Zimbabwe made it worse; nurses have for a long time (before HIV) been instructing women to exclusively breastfeed for the first six months, and the general response in communities is to ignore that teaching and give porridge within a few days because 'the baby will be hungry'. As a result, even women who did not feel that their babies were hungry were under pressure from people they lived with to give porridge. If the baby cried the people would complain that the baby was crying because s/he was hungry and would scold the woman for not giving porridge. This was a dilemma for some women: on one hand they had a baby they felt was hungry and would benefit from porridge, and on the other hand they desperately wanted to follow instructions so as to protect the baby from HIV.

*So I am confused because there are times when the baby cries because of hunger and I can really see that there is not enough breast milk...the baby is not getting enough milk. Maggie, 33-year old married mother of three*

Women also complained that in some cases the people they lived with would give other foods; this was especially prevalent in women who had not disclosed their status to people they lived with. They were not taken seriously if they just said the reason they were

exclusively breast-feeding was that nurses had told them to do so. *“They say, “A-ah nurses are always saying that, but we gave our children porridge and nothing happened.”* Because of fear of stigma women found it difficult to explain that exclusive breastfeeding was important for PMTCT purposes, and were forced to always have their babies with them, even when it would have been more convenient to ask someone to watch the baby for a few moments. *“I should never take my eyes off the baby.”*

Despite the above challenges none of the participants reported that they practised mixed feeding. The majority exclusively breast-fed; only two women were giving formula milk.

Participants who came from families that traditionally breast-fed their babies in the first six months of life had no problems with exclusive breastfeeding. For example Fungai reported that her mother-in-law has always insisted that a woman should breast-feed exclusively in the first six months; this is what she did with her first two babies, so exclusive breastfeeding with the third child was not a challenge as she was used to it. *I had no problem because with all my children...in fact my mother-in-law always says she does not want to see any of her family’s babies eating porridge soon after delivery.*

The other challenge women faced was worry about what they would feed their babies after six months. The study was conducted when the clinic was transitioning from teaching that HIV positive women should stop breastfeeding at six months to the AFASS guidelines (conditions to be met if replacement feeding is to be given to babies. These include the availability of safe water and sanitation, assurance of continued supplies and ability to prepare and give the food safely: A-Acceptable, F-Feasible, A-Affordable, S-Sustainable, S-Safe). Some women were still with the old teaching and were worried that they had no food to give to their babies after the six-month period. Those women who were aware of the AFASS guidelines were worried about the continued exposure of the baby to HIV: *“We were told that when the baby is more than six months old s/he will get HIV because at that age s/he will suck-off all traces of milk that is in the breast.*

Many participants therefore wished they could get donations of formula milk.

#### **9.3.3.4 Anxiety about end of study participation**

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Some participants worried about their end of study participation; they worried about loss of confidantes as their participation in the study ended. Participants reported that the study had given them an opportunity to openly discuss their feelings about HIV, and they had found this

therapeutic. In most cases study staff were the first people that participants had openly discussed their HIV issues with.

*“Sister T was the first person I talked to about my HIV status.” **Fungai, 27-year old married mother of 3***

At the end of her in-depth interview, this was what Mucha said:

*I am thankful for this project, and these procedures you have been doing. You know...sometimes...when you are asked questions...when you find someone to talk to...sometimes I just long to speak to someone, someone I am free and comfortable with, what we have just been doing; it helps us have a better state of mind. **Mucha, 41-year old married mother of five***

In addition, participants were aware that their participation gave them privileged access to certain forms of care as the study nurse had more time. For example she counselled them and at times assisted them to get ‘privileged’ care for the nurses, like retrieving their results.

It was clear that more has to be done to set up structures that enable the social support of HIV positive women in Mbare. There is a support group for HIV positive individuals at Mbare Clinic and a friendship bench for the support of distressed individuals, but none of the interviewed women reported attending them. It could be the fear of HIV stigma in their crowded communities that deterred women from participating, suggesting that other methods of supporting recently diagnosed HIV patients should be sought.

#### 9.4 SUMMARY OF STUDY FINDINGS

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This study revealed that recently HIV-diagnosed women go through a lot of anxiety and distress around the time of diagnosis related to 1) coming to terms with their HIV status, 2) lack of husband support soon after HIV testing and for medication adherence, 3) fear of stigma and 4) health system factors like drug-stock outs and long queues at the clinic. The desire to ensure the health of their children has motivated these women to focus on adhering to CTX-p and other health care interventions. In addition, most women reported a striking inability of their male partners to confront HIV issues, which was driven by lack of knowledge, and likely, fear that HIV infection emasculated them in their partners’ eyes.

Interventions are required to lessen the emotional burden upon women at time of diagnosis. Many women reported feeling distressed after their HIV diagnosis. In many instances their

depression was compounded by lack of or incorrect knowledge about HIV, e.g. many thought they were about to die, and some did not know that it was possible to give birth to an HIV negative baby. The nurses providing antenatal care were overwhelmed and probably did not have enough time to educate the woman or go through with her what being HIV positive meant. The clinic has a friendship bench that provides psychosocial support to distressed individuals. None of the women used this service. Nurses may need to actively refer HIV positive women to this bench so that they access this care.

Interventions to encourage testing among male partners, particularly couple testing are required. This study found that men who had gone through couple testing and counselling had the model ideals and health seeking behaviours that public health professional would like to see. It is clear that male support is essential for the optimum uptake of all interventions along the PMTCT cascade, starting with ANC registration as discussed in Chapter 7. Potential methods of increasing male involvement in Mbare community, which have been employed in other settings, will be discussed more fully in the discussion chapter. Finding ways to encourage men to take a more participatory role within the family may be beneficial. There are some examples of interventions to encourage men to become more involved in parenting which will be discussed.

In addition to interventions for male involvement, communities in general should be further educated about HIV. This is especially important in order to dispel existing myths and provide up to date information on available health care interventions for people living with HIV. This might lessen the fear that communities have of HIV testing, and might also lessen the stigma that is common in communities like Mbare.

One of the main observations in this study is the unwavering determination of women to adopt health care interventions that they believed were beneficial to their children. This concept might be employed in health promotion messages. As observed in the last chapter, women do not pay much attention to interventions that are designed to benefit their own health but they are particular about interventions for their babies.

This study also highlighted the therapeutic effect of research studies in the context of limited social support. Study staff were in most cases the first people that participants openly talked to about their experiences since testing HIV positive. It was a privileged position to have participants open up about their circumstances and it is also humbling that while data were being gathered for research purposes the participants felt that the process was therapeutic.

This also highlights the limited social support that HIV positive women have in their communities, and should act as a driving force to find interventions that are aimed at producing communities that can openly talk about HIV without fear of stigma.

The findings of this chapter will be discussed more fully and in light of the other findings in the discussion chapter.

## **CHAPTER 10: DISCUSSION**

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### **10.1 OVERVIEW**

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This PhD project investigated health system and patient level barriers to the implementation of cotrimoxazole prophylaxis among infants born to HIV positive mothers. Barriers were investigated at policy level and at all stages of the cotrimoxazole care cascade, starting with identification of HIV exposure status during ANC, initiation of cotrimoxazole prophylaxis six-weeks postnatally and adherence to cotrimoxazole prophylaxis. Although this project focused on cotrimoxazole prophylaxis, the findings and implications do not relate to the issue of cotrimoxazole prophylaxis provision alone but to the whole package of services provided to HIV-exposed infants along the PMTCT cascade. Addressing the challenges to implementation identified by this study would likely result in improvement in PMTCT services in general. In order to understand the extent of challenges faced in implementing the PMTCT cascade more generally, a systematic review was conducted to investigate the magnitude of loss to follow-up of HIV-exposed infants from real-life PMTCT programs at various points along the PMTCT cascade.

### **10.2 SUMMARY OF STUDY FINDINGS**

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#### **10.2.1 Systematic review findings**

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There was significant heterogeneity in the reported loss to follow-up outcomes of the reviewed studies. Despite this it was evident that there is unacceptable loss to follow-up of infants from real-life PMTCT programs. An estimated 49% of HIV positive mothers are lost to follow up between ANC registration and delivery. Programmes which offered older PMTCT regimens (single dose nevirapine) reported greater losses than programmes which offered dual/triple therapy.

Among fourteen studies which reported loss to follow-up of infants by three months of age, the pooled estimate of loss to follow-up was about 34%. Another 45% of infants were lost after HIV testing; they either stopped coming for the recommended follow-up visits after testing, or did not return to collect results. At all stages of the PMTCT cascade that were studied in the systematic review, programmes which actively tracked defaulters reported

better retention outcomes than those which did not follow-up women-infant pairs who missed their appointments.

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### **10.2.2 Policy study findings**

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There was Government commitment to a nationwide, multi-sectoral response to HIV. Ministry of Health and Child Welfare (MoHCW) have formulated comprehensive guidelines for the implementation of cotrimoxazole prophylaxis, based on WHO guidelines. MoHCW had support from partners, e.g. EGPAF, Kapnek Trust, ZAPP, and OPHID who supported implementation of PMTCT services. In addition, the Ministry received funding for HIV services from bilateral and multi-lateral donors. However all this support at the macro level did not result in optimum implementation of cotrimoxazole at site level. Countrywide, only 34% of babies who needed cotrimoxazole prophylaxis received it in 2010. At Mbare Clinic, several barriers to implementation were uncovered, which included: shortage of staff, inadequate training of site staff on specific procedures for implementation, poor supply chain management possibly because of lack of training of clinic nurses and logistical challenges at the main City of Harare pharmacy. Other challenges reported by clinic nurses were patient-specific: some women were lost to follow-up at the six-week visit because they were having challenges adjusting to their newly diagnosed HIV status. The department that was responsible for home follow-up of such women was short-staffed and overwhelmed by work, and this challenge was compounded by the fact that women often gave false home addresses. It was clear that the strong commitment to provide cotrimoxazole at the macro level was insufficient in itself to ensure implementation; there was need for support to continue to be 'cascaded' down to site level to ensure optimum implementation. It is likely that some of the challenges were caused by the economic challenges that afflicted the country between 2003-2010 : many experienced workers left the country to seek employment elsewhere, and there were insufficient financial resources to hire as many new employees as were required.

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### **10.2.3 Findings from studies of the cotrimoxazole prophylaxis cascade**

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The first challenge observed was entry into the cotrimoxazole care cascade: 23.4% of women did not seek ANC, a critical step of the cascade where health care workers are alerted of the HIV exposure status of the infant. Those women who registered generally did so very late in their pregnancy; mean number of weeks gestation at time of registration was 29.5 (95% CI 28.6-30.4). In multivariable analysis, factors associated with ANC registration were



education, which interacted with whether the pregnancy was planned, household income and marital status. In the qualitative study, women reported the following were barriers to ANC registration: user fees, fear of HIV testing and associated stigma if tested HIV positive, unsupportive husbands/male partners, nurses' poor communication, long waiting times at the clinic and unplanned pregnancy. These factors interacted with each other in a complex way.

There was poor attendance at the six-week visit, the clinic visit where babies are supposed to be initiated on cotrimoxazole prophylaxis. Overall only 20% of women attended the visit; and 35% of Mbare residents attended. There was no association between six-week visit attendance and maternal HIV status. Women who registered for ANC were three times more likely to attend the six-week visit than those who did not. Qualitatively, the main reasons for non-attendance were lack of appreciation of importance of the six-week visit for the baby; and that women valued the health of the baby above their own. Distrust of nurses particularly in relation to unintended HIV disclosure was also reported as a barrier to attendance.

In the adherence study, again it was evident that women valued the health of their babies and were determined to do all they could to adhere to their baby's cotrimoxazole prophylaxis along with any other medicines that had been prescribed. Barriers to adherence included unsupportive husbands, fear of unwanted HIV disclosure and associated stigma and health system factors like drug stock-outs, long queues at the clinic and disparity between dispensed amounts of cotrimoxazole and the next appointment date for prescription refill. The adherence qualitative study also highlighted that HIV positive women experienced significant anxiety/anguish, first with coming to terms with their own HIV status along with unsupportive husbands and constant fear of unwanted HIV disclosure in a community that was viewed by the women as highly unsupportive of HIV positive people.

### **10.3 DISCUSSION OF STUDY FINDINGS**

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Before going into discussion of the findings, it is important to highlight the main limitation of the study, which is important for understanding the implications of the study findings. The study was conducted at one clinic, which might not be representative of the other health care centres in the country. However, it may represent the best of what was happening in the public health setting at that time. City of Harare rates Mbare Clinic as one of their best clinics; it is often referred to in the media as one of the model clinics in Harare. This is confirmed by the fact that half of the women who deliver at the clinic are not residents of

Mbare, but are women who opt to travel from clinics in the neighbourhoods in which they live so that they can seek the services at Mbare Clinic. Interviewed nurses reported that Mbare Clinic was viewed by clients as more organised, and less likely to have drug stock outages than others in Harare.

A discussion of specific study findings now follows.

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### **10.3.1 Policy findings**

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#### **10.3.1.1 Adoption of policy at national level does not guarantee optimum implementation**

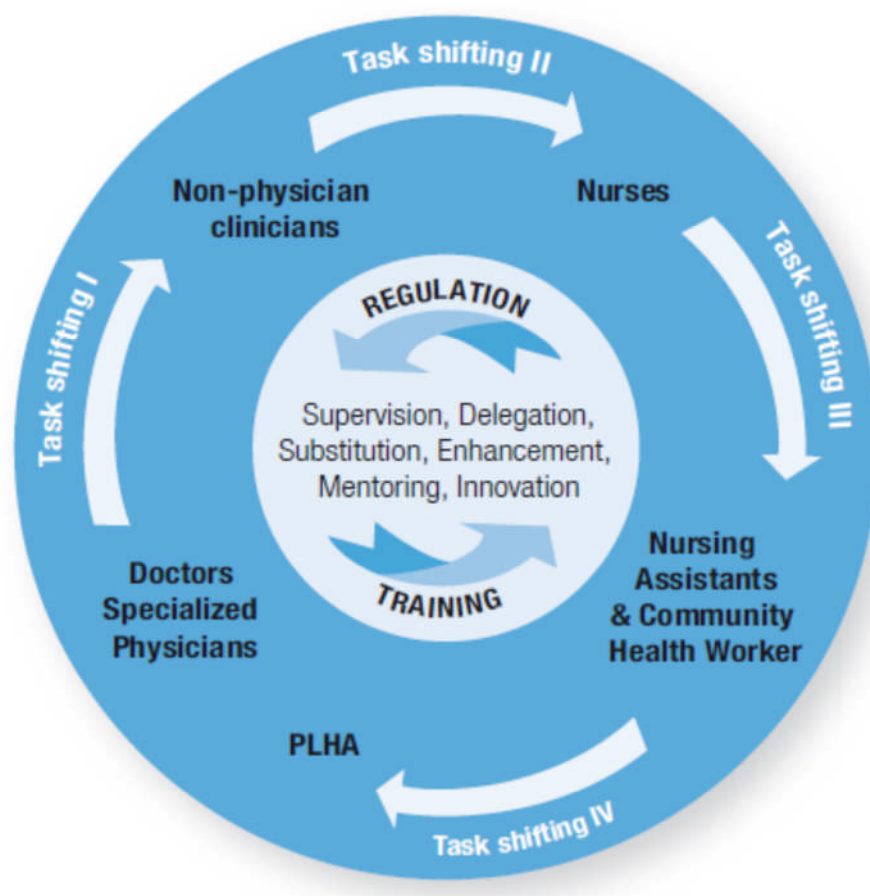
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This study was conducted at a time when cotrimoxazole prophylaxis had already been widely adopted as an important intervention at national level in Zimbabwe. The challenges related to adoption of research findings on cotrimoxazole prophylaxis into policy, as reported in Malawi, Zambia and Uganda<sup>40,41</sup> had already been overcome, yet this did not result in successful implementation at health care centre level. This teaches us that adoption of policy at national level is insufficient to achieve good results; there needs to be sufficient follow-up and support at every stage of implementation to ensure adoption of policy recommendations.

As reported in Chapter 5 (policy study), official record review of Ministry of Health documents revealed that the main challenge preventing optimum implementation was financial<sup>122,136</sup>; the country was recovering from a politico-economic crisis. Inability to hire and retain adequate numbers of trained health care workers meant that the fewer health care workers were overwhelmed with duties, which limited their ability to provide quality health services. Although efforts had been made to mobilise financial resources for the national response to HIV, there was still a gap in funding which prevented hiring of adequate numbers of health care workers and adequate funding of health services. Continued mobilization of resources to the health sector is therefore required. Zimbabwe is a signatory to the Ouagadougou Declaration which emphasises incremental funding of health systems up to 15% of the national budget by 2015<sup>125</sup>. Health expenditure has for a long time been one of the top 5 priorities of the country's national budget<sup>122</sup> and indeed Government is regularly commended for its National AIDS Trust Fund (NATF) introduced in 1999 to increase Government's ability to finance its HIV response. However in an ailing economy this proved insufficient; other methods of managing resources need to be considered. For example there is need for better efficiency in the use of both national and donor funds. That NatPharm indicated there were plentiful supplies of cotrimoxazole (from more than seven donors), such

that they were worried the drug could expire could suggest excess supplies due to duplication in funding. The Paris Declaration, in which Zimbabwe also subscribes<sup>122</sup>, calls for promotion of efficiency through avoidance of duplication in funding<sup>146</sup>. At the time of this study Zimbabwe had begun this process of harmonisation of funding from donors through the Expanded Support Programme which was funded by several donors for HIV services<sup>122</sup>, but more still needed to be done. Efficient use of resources will result in savings that can be used for other critical resources like human resources.

One approach to tackling the issue of limited resources other than to employ suitably qualified staff is to consider task shifting. WHO has recommendations for task shifting across all levels of qualification and competency to address health care worker shortages and improve the delivery of HIV and AIDS services<sup>147</sup> (figure 10.1).



*Fig 10.1: WHO guidance on task-shifting in the health sector<sup>147</sup>*

Task shifting has been undertaken in several countries without compromising safety or quality of services<sup>148-151</sup>. For example it has been successfully implemented in Uganda, Democratic Republic of Congo, Malawi, Ethiopia and developed countries like UK, USA and

Australia.<sup>147</sup> In Zimbabwe, task-shifting of counselling roles from nurses to lay counsellors is being implemented at varying levels across health care centres around the country, and has been found to be acceptable to patients<sup>152,153</sup>. At Mbare Clinic, we found relatively little evidence of task-shifting of nurses' roles. The primary counsellor cadre, which has been widely introduced in public health centres to relieve nurses of non-clinical HIV-related duties, has not been introduced within the City of Harare system. In addition to primary counsellors, City of Harare might consider recruiting lay volunteer counsellors who can also help to reduce nurses' workloads. Allowing nurses to concentrate on the more clinical duties might address some of the challenges related to workload that have been identified in this study: it might result in greater ability to train staff on new policies and procedures, fewer omissions while caring for patients, more compassionate attitudes towards patients and better quality service provision in general.

#### **10.3.1.2 Poor supply chain management**

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It is worrying that during the course of the study (16 months) at Mbare Clinic there were four periods (sometimes lasting up to three weeks) of cotrimoxazole stock outage while the national stores had excess cotrimoxazole which they worried would expire before use. Cotrimoxazole is classified in the Zimbabwe essential drugs list as a vital level C drug, which means that it is expected to be 100% available at all levels of care. Although not specifically explored in this study, this finding raises concerns that sub-optimal stock management may extend to other drugs and supplies used at the clinic, which could potentially include supply of ARVs given that the clinic is an ARV follow-up site. Stock outs also prevent provision of essential services at the clinic: for example there was a time at Mbare Clinic when babies were not being offered EID because the required DBS filter papers were not in stock. The challenge with supply-chain management is not limited to Mbare Clinic, but is a countrywide problem; NatPharm, MoHCW and its partners are aware of this challenge and have attributed it to shortage of experienced staff following the country's politico-economic problems. A 2005 countrywide logistics system assessment found that most health care sites in Zimbabwe did not have proper procedures for supply chain management and many drugs and supplies regularly went out of stock. Most sites did not have cotrimoxazole in stock, and those that had it had very small amounts<sup>154</sup>. Recommendations for staff training in logistics management were made but have yet to be implemented. To solve the problem in the short-term, at the time the study was conducted NatPharm was sending pre-packaged primary care kits which contained all the necessary drugs and sundries for primary level centres to

district/rural health centres on a quarterly basis. They did not wait for the districts to place orders themselves. This was being done for rural health centres; clinics run by the City of Harare were not included, resulting in the stock-outs at Mbare Clinic.

In addition to the urgent need for staff training on supply chain management, other logistic challenges to timely drug provision exist. For example the City of Harare main pharmacy was reported to have transport problems for the delivery and collection of supplies (Chapter 5). Furthermore, staff shortages are likely to compound the problem.

### **10.3.1.3 Gaps in provision of staff training on new implementation guidelines**

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We found that while some clinic staff had been trained in new policy guidelines, others had not. MoHCW trains few staff members who are in turn expected to cascade training to their colleagues at the sites. In practise this is difficult in a short-staffed clinic where staff will be too busy to train one another, leading to service provision by untrained workers. In this study some errors were noted which were possibly due to lack of staff training, e.g. omissions of ARV or cotrimoxazole prophylaxis, prescription of incorrect duration of infant ARV prophylaxis or wrong dosages for cotrimoxazole prophylaxis. MoHCW might consider implementing procedures that ensure training of all site staff. For example MoHCW might train a large group of trainers who in turn provide training to all staff at specific health care centres. In addition, clinics could implement procedures to minimise the chance of staff who have not received training from conducting key clinical duties. For example staff might be required to read the guidance documents and provide evidence that they have done so. MoHCW could then look for this evidence when they undertake their support visits. In addition to ensuring that all staff are trained, this site-specific training could enhance team working amongst clinic staff: a study conducted in Zimbabwe in 2010 found that selective training of staff members off-site often resulted in discord because there were financial benefits for attendance of training meetings in the form of travel and subsistence allowances. Staff who did not attend the training meetings felt left out of the benefits and did not feel it was their responsibility to provide services they had not been formally trained to do<sup>153</sup>.

I will now turn to discussing findings from the cotrimoxazole care cascade; this will be integrated with findings from the systematic review which also looked at a similar cascade.

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### 10.3.2 Discussion of findings from the cotrimoxazole care cascade

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As discussed in previous sections, many factors were found to contribute to attrition along the cotrimoxazole prophylaxis cascade. These include user fees, fear of HIV testing, unsupportive male partners, HIV-related stigma, and relationship between nurses and clinic attendees. These will now be discussed in turn in the following sections.

#### 10.3.2.1 User fees

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User fees presented a huge barrier to entry into the cotrimoxazole cascade; all participants in the ANC qualitative study reported this as a barrier which accounted for both late registrations and non-registrations. A possible solution to this challenge is removal of user fees, a process that Government has begun using the Health Transition Fund<sup>128</sup>. Many studies, including systematic reviews have shown the positive impact of removal of user fees on uptake of health services in countries in Sub Saharan Africa including Zambia, Niger, Ghana, Uganda and South Africa.<sup>155-157</sup> However lessons learned from these countries indicate that careful planning should be undertaken before abolishing user fees.<sup>158-160</sup> There is need to forecast the impact of abolishing fees on demand of health care services, and resources such as drugs and human resources, followed by mobilisation of sufficient funds to support this process and ensure sustainability. Removal of user fees without proper planning can result in significant strain on the health system and poor quality outcomes. For example, when the Government abolished user fees in public health care institutions in Zimbabwe in 2012 there was chaos in one of the central hospitals in Harare as a large number of women went to deliver there; the hospital could not cope with the increased numbers because it was not adequately staffed and there were insufficient beds; some women were forced to give birth on the floor<sup>161</sup>. Also, when user fees were reduced at Mbare Clinic from \$50 to \$30 in 2011 nurses complained that the increase in number of women accessing maternity services was difficult to cope with, and may have had an impact on the quality of services provided. In the interim while the challenge with user fees is being addressed, City of Harare might consider accepting the registration fees in small instalments that women can afford.

To encourage attendance of all antenatal and postnatal visits the City of Harare Health Department has a flat maternity fee rate which covers all antenatal and postnatal care up to the six-week visit. Although the fee itself may be a barrier, once women have got together the money to pay for ANC they are more likely to attend post natal visits: in this study women who registered were three times more likely to attend the six-week visit than those who did

not; addressing the challenges with user fees might increase attendance of the six-week visit. A study in India also found that women who registered for ANC early were retained in the PMTCT programme better than women who registered late<sup>89</sup>. This may be because increased contact with health care workers exposed the women to education, support and counselling which may have caused them to have better appreciation of the importance of adhering to clinic appointments. In addition, it may have increased client connectedness with the health care system, a phenomenon that has been reported to be associated with lower rates of missed clinic appointments<sup>98</sup>. Also, women who register early have already demonstrated that they have positive health seeking behaviours than those who do not; they can be predicted as most likely to attend for postnatal services in terms of their behaviour.

Zimbabwe is preparing to begin implementing the WHO Option B+ programme (where all HIV positive pregnant or lactating women are given ARVs which are continued for life); it is anticipated that this implementation will begin at the end of 2013 or early in 2014. The continued interaction with women when they collect their prescription refills may help increase retention rates along the PMTCT cascade for the same reasons mentioned above. Results from the Malawian Option B+ programme indicate encouraging retention rates of 77% 12 months after initiation of ART among women who did not transfer care during follow-up. Retention of mothers in care will likely reduce MTCT and likely also keep the HIV-exposed infants in care.<sup>99</sup> Related to this, the recent recommendation by WHO to initiate HAART at a higher CD4 count threshold might result in better retention rates for the same reasons mentioned above.

Another challenge which not only affected entry into the PMTCT cascade but also adherence to cotrimoxazole prophylaxis, was fear of HIV testing, which will be discussed in the next section.

#### **10.3.2.2 Fear of HIV testing**

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At Mbare Clinic HIV tests are offered to all women who register for ANC. 99% of women who registered knew their HIV status. This may be evidence of the effectiveness of the opt-out strategy of HIV testing in getting high acceptance rates for HIV tests. Many research studies in Sub-Saharan Africa have documented the superiority of the opt-out strategy over the opt-in model in the uptake of HIV testing.<sup>153,162-165</sup>

Unfortunately, the high uptake of HIV testing at Mbare Clinic was not all good news; there was evidence that women did not feel able to opt-out of testing. This is a drawback particularly in a community where the fear of HIV testing is rife, as reported in qualitative interviews. Similar findings have been reported in other settings. In rural Uganda women are believed to have stayed away from the ANC clinic because they were not aware that they could opt-out of HIV testing<sup>166</sup>. In South Africa, there were reports that women felt coerced by nurses to get tested, which resulted in some of them ‘running away’ from the clinic<sup>167</sup>. In Kenya women were reported not to be aware that HIV testing was optional<sup>168</sup>. WHO guidelines on HIV testing are clear that the offer of HIV testing should not be coercive<sup>169</sup>. Health systems need to ensure that HIV tests are offered in a way, and in an environment, that allows autonomy in HIV testing. This is not only important from a human rights perspective, but also to ensure that women who do not want to get tested for HIV feel able to seek antenatal services. Likely, if women who choose not to test are retained within the health care system, the continued education, counselling and support from health care workers might enable them to take up HIV testing at a later stage. Related to this, it is likely that education campaigns have emphasized the importance of PMTCT services during ANC so much that communities are no longer aware of the other benefits of ANC that are not HIV-related, but have a polarised view of the ANC clinic as an HIV testing clinic. Education campaigns emphasising the importance of ANC from a holistic perspective may help overcome some of these issues.

It is disturbing that HIV testing, the entry point to the PMTCT programme, is the very thing that keeps some women away from ANC. It is clearly critical to understand the fear of HIV testing and find ways of addressing it so that women will feel able to get tested. That women associated an HIV diagnosis with imminent death shows a lack of understanding of HIV disease and available interventions for saving lives of HIV infected individuals. Education campaigns to sensitise communities about this might be beneficial. Of note, these educational campaigns have been happening in Zimbabwe for some years. There may be need to find other strategies to deliver messages in a way that engages women from poor communities such as Mbare. However we already know that education on HIV disease and available interventions alone is unlikely to be sufficient to convince people to get tested as there is fear of HIV stigma, discussed below. Some studies have shown that the fear of HIV testing is sometimes so strong that it overrides all the potential positive effects of HIV testing, causing people to choose not to test.<sup>170,171</sup> In this study, the fear of HIV testing was found to be the



main factor limiting men's ability to support their partners to take up services along the PMTCT cascade. This will now be discussed in the next section.

### 10.3.2.3 Unsupportive male partners

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In this study women reported that their male partners had serious challenges with HIV testing, either of themselves or their partners. It is likely that men felt that HIV testing and diagnosis might threaten their masculinity. Other studies in Zimbabwe have reported that men see HIV as a threat to their manhood, which is associated with unwillingness to use health services and denying their partners access to HIV-related health care.<sup>172-174</sup> In Malawi men reported that a woman could be divorced if she tested for HIV without the husband's consent<sup>175</sup>. Interventions are needed that will help men feel that HIV testing can enable them to have control of their disease and their life i.e. that HIV testing is empowering rather than emasculating. Education/messaging that emphasises how HIV testing can help a man achieve his 'manly' roles may be beneficial, e.g. accessing treatment after testing HIV positive will help maintain the man's health and enable continued participation in masculine roles like working for the family. Of note, several media campaigns in Zimbabwe have tackled issues related to what constitutes a 'real man' e.g. PSI Zimbabwe have tackled the issue of sexual violence with advertisements that say that 'real men' are not violent to their wives and do not force women to have sex with them. Again effort needs to be made to ensure that such messaging is packaged in a way that makes sense and is accessible to men in poor communities like Mbare.

Couple testing and counselling might be effective in allaying some of the fears that men have about HIV testing. In this study, men who had undergone HIV testing and counselling, particularly as couples, were reported to be more supportive of uptake of PMTCT services. Similar findings have been found in other African countries; in Tanzania<sup>176,177</sup>, South Africa<sup>178</sup> and Kenya<sup>179</sup> women whose male partners had undergone HIV testing and counselling at the clinic where the women were enrolled for PMTCT were found to have better uptake and adherence to PMTCT services. Unfortunately, in these settings it was a challenge to get more men to come and get tested at the ANC sites, signifying the importance of promotion of male-friendly HIV testing and counselling sites outside ANC sites. In Democratic Republic of Congo there was greater uptake of HIV testing by men in bars than in health care centres where their pregnant female partners were being attended to<sup>180</sup>. Besides promotion of couple counselling and testing, there is very little literature on interventions that

can be employed to promote male involvement in PMTCT programmes. A 2012 Cochrane review on this subject found only one eligible study which evaluated an intervention to increase male support<sup>181</sup>. Women in the intervention arm received a letter which invited their male partners to come to the clinic for HIV testing and counselling<sup>177</sup>. The study found that women who were tested as couples were more likely to use preventive measures against transmission (90% vs 60%) and were more likely to receive single dose nevirapine for themselves or their babies, 55 vs 25% and 55 vs 22% respectively, although there was reduced uptake of HIV testing in the couple VCT arm. There is need for development and evaluation of more interventions to improve male involvement in PMTCT programs.

#### **10.3.2.4 HIV-related stigma**

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HIV-related stigma played a significant role in the uptake of services along the PMTCT cascade. It limited women's ability to register for antenatal care, attend the six-week visit, and adhere to cotrimoxazole prophylaxis for the baby. This is not the first study to demonstrate this effect: studies in Kenya<sup>94,182</sup>, Zambia,<sup>183</sup> South Africa,<sup>184</sup> India<sup>185</sup> and other countries<sup>186</sup> have shown that women might avoid ANC registration, HIV testing and facility-based delivery because they fear testing HIV positive and consequent stigma. A recent systematic review found that HIV-related stigma has a significant negative impact on service uptake along all stages of the PMTCT cascade<sup>186</sup>. The authors of the systematic review came up with a conceptual framework that illustrates the mechanisms through which stigma can result in negative outcomes for the HIV positive mother and her children (figure 10.1). The psychosocial effects of stigma result in poor health-seeking behaviour and poor health outcomes.

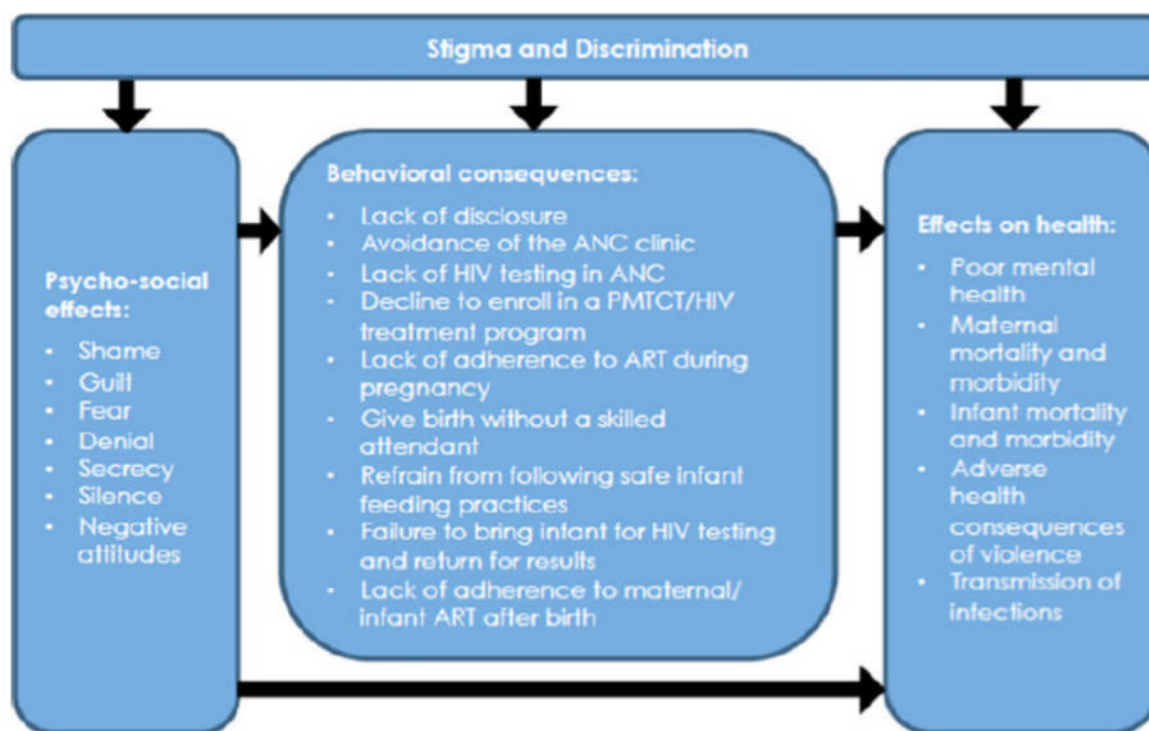


Fig 10.2: A framework for the effects of stigma on maternal, neonatal and child health<sup>186</sup>

There are various forms of HIV stigma that have been identified in the literature, including 1) self-stigma or internalised stigma, which is a feeling of self-blame or self-deprecation because of HIV infection, 2) Perceived/normative/felt stigma refers to fears or expectations that people have about being stigmatised in the event that their HIV status is known, and 3) enacted stigma, which refers to the actual experience of being discriminated against because of HIV or suspected HIV<sup>183,186</sup>. The three qualitative studies that were conducted as part of this project (barriers to ANC attendance, barriers to six-week visit attendance, and adherence study) all revealed that women were aware of the existence of enacted stigma in their communities, having heard accounts of people who had suffered it, or seen it inflicted on other people, or having previously inflicted it themselves. A new kind of stigma, called vicarious stigma, has been identified<sup>185,187</sup>: it describes the channel of communication about enacted stigma in the community, and is the basis for perceived/normative/felt stigma. Even if the HIV positive person has not personally experienced enacted stigma, the communication around enacted stigma in the community makes it more salient, and heightens the HIV positive person's fear of HIV disclosure, which is perceived/normative/felt stigma. Vicarious stigma was the main kind of stigma that was reported in this PhD project: there were few instances where participants reported personal experiences of enacted stigma, but there was extensive reporting of fear of stigma that resulted from discussions/perceptions of enacted

stigma on other people in the same community.

To increase the uptake of PMTCT services, it is important to scale-up stigma reduction interventions in the country, particularly to poor and crowded communities like Mbare where the effects of stigma are more salient. Stigma interventions have been classified into four categories: 1) informational approaches to give information on HIV disease, transmission and methods of reducing risk of acquisition, e.g. through mass media, educational lectures etc; 2) skill building, where potential perpetrators of stigma are given skills of how to interact with HIV positive people, 3) counselling/support to help HIV positive individuals to cope with the disease, e.g. in support groups, and 4) testimonials from people living with HIV<sup>188,189</sup>.

Systematic reviews have found these approaches to work in reducing stigma<sup>188,189</sup>. However many of the studies were not rigorously evaluated, and very few studies have been conducted in developing countries. There is need for rigorously evaluated stigma reduction strategies in settings similar to Zimbabwe, followed by scaled-up implementation of evidence-based interventions. A lot of stigma-reduction activities are already going on in the Zimbabwe, e.g. mass media campaigns, teaching about HIV in schools, and the National Behaviour Change Programme, but more still needs to be done to achieve communities with low stigma levels. Stigma reduction is particularly important for PMTCT programs because statistical modelling has shown that stigma accounts for more than half (53%) of vertical infant HIV infections, and that scale-up of stigma reduction interventions can avert 33% of all mother-to-child transmissions.<sup>186,190</sup>

In addition to stigma reduction activities in the communities, Mbare Clinic could do more to ensure that their clinical activities are undertaken in a manner that assures clients of confidentiality and decreases risk of HIV disclosure. While the chronic disease clinic offers efficiency given the staff shortages, it has a major disadvantage in that it has been labelled as an HIV clinic, which deters HIV positive patients from accessing care. The City of Harare might consider integrating this clinic with the general outpatients' clinic so that clients feel less worried about the possibility of unwanted HIV disclosure.

### 10.3.2.5 Relationship between nurses and clinic attendees

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Qualitative interviews showed that nurses' discourteousness affected all stages of the cotrimoxazole care cascade. Not only did it result in some women staying away from the ANC clinic altogether, but it also resulted in those that did attend feeling unable to ask questions about theirs or the baby's care if they did not understand. We documented several instances where opportunities to minimise risk of mother-to-child infections were lost. For example we found that women whose HIV infection is not diagnosed because they did not attend ANC are unlikely to get PMTCT interventions. Additionally, women who are unable to request prescription refills are less able to adhere to medication. Health care worker discourteousness has also been reported to affect uptake of PMTCT or ANC services in Cote d'Ivoire<sup>97</sup>, South Africa<sup>191</sup> and in a recent systematic review on barriers to poor usage of ANC services in low and middle income countries<sup>96</sup>. It is therefore critical that health care workers are trained on good client relationships. In addition, to ensure that staff do their work well, health care systems might consider introducing systems for rewarding health care workers who do their job well, and discipline those who do not. One strategy that has been employed to improve the performance of health care systems is results based financing or pay for performance, which refers to transfer of money or provision of material goods conditional on achieving a certain target, e.g. delivery or utilisation of services, patient outcomes or quality outcomes<sup>192</sup>. There are large pay for performance programs in UK, USA and Australia<sup>193</sup>. There are fewer and smaller programs in low and middle income countries, but there are some that have been successful, e.g. a programme in Rwanda provided health system bonus payments based on quantity and quality of key maternal and child welfare services. This resulted in improvements in numbers of institutional deliveries, uptake of preventive child services and quality of services provided<sup>194</sup>. Positive outcomes of performance-based payment on quantity and quality were also reported in Democratic Republic of Congo, showing the feasibility of implementing such a system in a very poor and troubled nation.<sup>195</sup>

Addressing staff shortages and work load as discussed in section 10.3.1.1 might result in improvement in nurses' wellbeing and mood, which might help them to be more sympathetic towards patients.

One of the problematic nurse-client interactions was referral to Harare Hospital for labouring women. Because nurses referred women against a background of poor communication,

especially after having been shouting at the women for ‘bad behaviour’, women construed the referral as punishment. Women reported that nurses did not adequately explain their reason for referral to either themselves or to the hospital where the woman was being referred. Nurses need to understand that this is how referral is sometimes interpreted. This is important because pregnant women have already devised strategies not to register in order to save money in the event of referral. Clearly nurses need to communicate professionally and ensure that their clinical decisions have been understood by their clients. Also, women need to be referred with proper documentation of the reason for referral so that the receiving health care worker will know how to manage the patient. Good clinical communication is critical to optimise patient care.

Interviews indicated that there was widespread discussion about the nurses’ perceived attitudes in the community, which reportedly reduced women’s attendance of the clinic. This suggests that to improve uptake of services perceptions within the community will need to be altered. Findings from this study point to the effectiveness of client testimonies in disseminating information within the community so changes in attitudes and behaviour brought about through awareness training would likely be quickly communicated. Improvement in community perceptions on nurse attitudes might also result in an increase in couple counselling and testing and male involvement; studies in Uganda<sup>196</sup> and South Africa<sup>197</sup> have reported that men do not take up couple testing at clinics because of their perception about nurses’ attitudes.

In addition to interventions to improve health care worker attitudes, patients and clinic attendees need to be made aware of their rights and the kind and quality of services they should expect to receive from health care workers. To improve patients’ ability to demand the health care they deserve, health care systems need to explore ways of ensuring that patients feel comfortable to ask questions or to request services from nurses. Patients should be taught about their rights and how to exercise them. Patient charters can be a useful way of introducing this. Although Zimbabwe has had a patient charter since 1996, more needs to be done to ensure that the public are aware of it and what it means<sup>198</sup>. In addition, there is need to develop and implement a patient-friendly system for addressing grievances. The government of Zimbabwe might consider implementing an ombudsman system that will actively deal with patient rights and patient complaints from all levels of care, as has been done in UK<sup>199</sup>.

### 10.3.2.6 Improving retention along the PMTCT cascade

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The systematic review in Chapter 2 revealed that health care systems that had effective methods of tracking defaulters had better retention outcomes than those that did not. To improve the follow-up of women at the six-week and other regular PMTCT visits, Mbare Clinic might consider strengthening strategies for follow-up of women who have missed their appointments. Fortunately, provisions for this are already in place; a department for community follow-up of patients exists but has not been actively tracking defaulters because of short-staffing and high workload. Increased use of the lay workers, the health promoters who are employed by City of Harare for this purpose might be beneficial. While the issue of staffing is being sorted a more immediate solution might be follow-up of defaulters using text messages. The majority of Zimbabweans now have access to a mobile phone; the reported tele-density in Zimbabwe in 2012 was 90%<sup>200</sup>. Importantly, tracking efforts should ensure that confidentiality is not compromised. The PhD project did not investigate loss to follow-up of HIV positive women between ANC registration and delivery; however the systematic review showed that an estimated 49% of women might be lost at this time. Tracking of missed appointments can therefore not be over-emphasised. A potential challenge with tracking is the false locator/contact details given by women. Reasons for this need to be investigated and if possible addressed. In our study the reason behind giving false addresses was related to fear of unwanted HIV disclosure, and nurses reported that sometimes women who come from outside the Mbare clinic catchment area give false addresses because they fear that the clinic will turn them away. Implementation of stigma-reduction interventions in the communities as described in Section 10.3.2.4, and addressing challenges with catchment areas might lessen this problem.

Qualitative findings about the six-week visit indicated that the main barrier to six-week visit attendance was lack of knowledge of importance of the visit for the baby. This is a relatively straightforward knowledge gap to bridge. It was clear from all qualitative interviews that women value the health of their babies and would do anything to ensure uptake of interventions for the benefit of the baby. Of note, women were less able to prioritise their own health, for example they did not see the importance of the maternal health services offered at the six-week visit. Given the commitment of women to their babies' welfare, educational messages that brand maternal health services as important not only for the mother but also for the benefit of her babies might increase uptake of maternal health services.

Another challenge with continued follow-up of woman-infant pairs is the non-integration of maternity services and chronic diseases clinic. Women were referred from the maternity services to the chronic care clinic, which was in a different building, where long-term HIV care for the infant and the mother was provided, and nurses worried about the potential for loss to follow-up. A study in Mozambique documented that there was significant loss to follow-up as a result of referring clients from one building to another, even if it was at the same institution. The health care workers at that hospital devised a simple intervention where women who were referred were physically accompanied to the referred site (EID site), and this resulted in a three-fold increase in the odds of uptake of EID services<sup>76</sup>. Mbare Clinic might consider using lay volunteers or health promoters for this purpose. Related to this, the systematic review revealed that some infants were retained in the immunisation services but not in HIV care, so they did not get EID. Integration of immunisation services and EID services might improve the retention of HIV exposed infants in HIV care.

#### **10.3.2.7 Positive views about cotrimoxazole prophylaxis**

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This study revealed that women had very positive views about cotrimoxazole prophylaxis, and this encouraged continued adherence. Positive views on cotrimoxazole prophylaxis were also reported in the ARROW study, which was conducted in Zimbabwe and Uganda<sup>9</sup>. That study found that 25% of caregivers refused to participate in another randomisation in the trial (study arms were either continued or stoppage of cotrimoxazole prophylaxis among children who were stabilised on ART) because they believed in the effectiveness of cotrimoxazole, having seen its benefits during the period before their children had access to ART. The perceived good health of the baby that is attributed to cotrimoxazole can result in a virtuous cycle: perception that the intervention is working provides motivation which encourages further adherence to all interventions along the cotrimoxazole care cascade. There is need for health systems to demonstrate success at each stage of the PMTCT cascade because this provides impetus for increased commitment to adherence.

I will now briefly discuss the HIV care of HIV positive women who participated in the study.

#### **10.3.3 HIV care for mothers**

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One of the limitations of this study is that there were small numbers of HIV positive women who were followed-up, so it was not possible to study the factors affecting successful



enrolment of the mothers into regular HIV care. Despite this it was noted that women who did not return to the clinic at six weeks were generally not enrolled in HIV care, while those who were in regular follow-up at the clinic had received more care. This further underscores the importance of follow-up of defaulters as discussed above. Qualitative interviews suggested that not having come to terms with one's HIV status can affect the ability to seek HIV care. This points to the need for support and counselling of women after HIV diagnosis to help them cope with the new diagnosis. At the beginning of the study, some HIV positive women had challenges accessing HIV care for themselves because they could not afford the \$6 consultation fee. Fortunately this fee has now been removed. This goes further to show that user fees can have a negative impact on access of services among the poor.

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#### **10.3.4 Reflexivity (for qualitative studies)**

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Interviewed participants were aware that the study team were health professionals who were not part of the team at Mbare Clinic. This identity of the researchers might have enabled participants to talk about intimate details of their lives which they would normally only share with a trusted health professional. This was possibly one of the factors that enabled the study team to get an in-depth understanding of the women's reality. Because women were willing to go into specific detail about the care they had received the study team was better able to study the adequacy of the health care that the woman or her baby had received. That the study team was viewed as external to the system also helped in that women felt able to give detailed accounts of things they were not happy with at the clinic, particularly the perceived inappropriate/inadequate clinical care (e.g. inadequate supplies cotrimoxazole) or treatment they reported receiving from clinic nurses. Also, the candidate (interviewer in the qualitative studies) fluently spoke Shona, the language that the participants used, and during home visits she appeared relaxed in the participants' poor surroundings, which might have helped participants feel free to talk and less aware of the difference in social class.

The view of the researcher as a health care worker might also have influenced participant accounts of their behaviour as they may have borne in mind what health care workers consider as 'good' patients. This might explain women's accounting around the fear of HIV testing and nurses' lack of compassion as barriers to ANC registration. None of the interviewed women were ready to admit that they may have stayed away because of either of these two factors, but they presented these reasons as general feelings among other women in their community. They were quick to point out that it was irresponsible not to seek ANC just

because of these reasons, and were keen to distance themselves from such actions. This was possibly because they wanted to be viewed by the interviewer as a responsible and caring mother with ‘good’ health-seeking attitudes.

In addition, for most HIV positive women study staff were the first people they opened up to about their HIV infection; it might have been the first time they processed their feelings about their HIV diagnosis and their experiences. As reported by some women this had a therapeutic effect, which may have caused women to pour out more from their inner selves than they would normally do. The result was the collection of vivid and often emotional accounts of what women went through in their life journey since the time they tested HIV positive.

The professional key informants (nurses, MoHCW, City of Harare and NatPharm representatives) understood the role of the candidate as a researcher. Being themselves educated individuals who had good jobs, they appeared to have a similar social class as that of the candidate. The fact that the candidate was viewed as knowledgeable around PMTCT issues made them go into much detail about the specific challenges that they faced with implementation.

The Ministry of Health correspondent was very supportive of the study, explaining that as a programmer she would need information on how the health care system could be improved. She seemed candid in her responses about the challenges that Ministry of Health faced as an institution. Likewise, City of Harare, NatPharm and the clinic nurses understood the importance of the research and seemed ready to talk about the institutional challenges that they faced in the implementation of cotrimoxazole prophylaxis. However, it is likely that they all might have also have viewed the research as something that had a potential to reveal bad practises on their part, which might have influenced how candid they were in their responses. As a result, more information might have been given on how institutions were failing, but less information on how they (as individuals) might have been failing in their duties.

#### **10.4 STRENGTHS OF THE STUDY**

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The main strength of this study was the ability to study various points of the cotrimoxazole care cascade in order to get an in-depth understanding of challenges affecting each part of it. Several studies including a systematic review were conducted. The multi-methods design was useful in elucidating the findings. There were plenty of opportunities for triangulation of findings from the various studies that were conducted.

Another strength of the study was its narrow focus on the cotrimoxazole care cascade, yet the findings are widely applicable to other interventions along the PMTCT cascade. This narrowing of focus allowed detailed evaluation of factors affecting uptake of the intervention; yet addressing such factors might result in improvement in uptake of PMTCT services in general.

The study provided a unique opportunity to investigate the reasons why there was sub-optimal uptake/implementation of cotrimoxazole prophylaxis in Zimbabwe. MoHCW and Harare City Health officials indicated that they were looking forward to getting the study report as they were hoping it would provide solutions to some of the challenges they have been grappling with. Optimal implementation of PMTCT interventions is an area of importance for MoHCW. The study findings were presented to City of Harare in 2011, and presentation to MoHCW and other partners is planned.

### **10.5 LIMITATIONS OF THE STUDY**

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As stated at the beginning of section 10.3, the main limitation of the study is that it was conducted at one clinic, which might not be representative of the other health care centres in the country. However, it may represent the best of what was happening in the public health setting at that time.

The policy analysis would have benefited from an examination of the contribution of key individuals to policy. Including the key individuals would have necessitated a close study of the individuals to get information on their values and motivations. The cost of this could not be supported by the small PhD fellowship. Also, the policy review could have benefitted from a survey of nurses where they could be questioned about the training (on the policy) they had received and knowledge of the guidelines on cotrimoxazole prophylaxis and care of HIV positive mothers. This would have enabled better understanding of how well guidelines are transmitted from Ministry of Health to clinic staff.

Another limitation is the small number of participants who were included in the cross-sectional survey; because of this many estimates were not precise. 299 out of 553 (54%) women were surveyed, and we were not able to get characteristics of those who were not surveyed. However the characteristics of surveyed participants were comparable with those of women in the retrospective clinic record survey, which suggests that the sample was

representative of women delivering at the clinic. A related limitation is the potential for selection bias because participants were recruited only during weekdays and during daytime hours, and also included women who attended the 10-day postnatal clinic, who might be different from non-attenders. The initial plan when the study was designed was to collect data only from the post-natal ward. It was however difficult to recruit women in the ward because they reported being too tired and feeling too much pain to go through interviews. A decision was then made to recruit from the 10-day clinic as well, which was less ideal given the potential for selection bias. It would have been helpful to compare the characteristics and responses given by participants who were recruited from the two different clinics (postnatal ward and 10-day clinic); however the data were not entered in a way that allowed this. Fortunately the similarity of the survey data and the data for the clinic record survey for six-week visit attendance suggests that selection bias was minimal, but we are not able to determine whether the timing of interviews (at delivery or at day 10) influenced participant responses.

Because participants were recruited from the clinic, the study only represents views of women who were engaged with the health care system; the barriers affecting women who delivered at home and did not access health services thereafter were not captured. At the beginning of the study we sought to understand the proportion of women who deliver at home: over a two-week period we asked the City of Harare community health workers (health promoters) to identify all deliveries that happened within their catchment areas, and the proportion that were home deliveries. The workers reported 8 of 58 (14%) deliveries had happened at home and the women had not sought any health care afterwards. These figures were interpreted with caution as it was evident that community health workers had not captured some of the deliveries that were known to have happened at the clinic (as shown in the clinic delivery records). However these data suggest that there were women who were totally unengaged with health services whose views were not captured in this study. They may have had similar challenges to those that have been reported, but may also have had different challenges that are unique to them.

Another limitation of the study was that not all stages of the PMTCT cascade were studied. This was mainly because of limited funding for the PhD fellowship. With adequate funding that would allow recruitment of larger sample sizes and longer participant follow-up, it would have been useful to look at uptake of maternal and infant ARV prophylaxis, uptake of early

infant diagnosis (EID) and uptake of ART among infants who tested HIV positive.

Another limitation of the study is that we did not get nurses' views/responses to concerns that participants raised. Although nurses were asked about challenges to implementation at the beginning of the study, a more balanced analysis may have been possible if nurses had been given an opportunity to respond to participant concerns/complaints. A related limitation was the inability to study BRIDH Pharmacy (the pharmacy that supplied drugs stocks to Mbare Clinic). Getting the perspectives of BRIDH Pharmacy staff would have provided a better understanding of the factors preventing continuous supplies of drug stocks at Mbare Clinic.

The limitations of the systematic review are discussed at the end of Chapter 3.

In conclusion, this study provided a unique opportunity to study health system and patient-level barriers to paediatric cotrimoxazole prophylaxis. Several contextual, health system and patient level barriers were found; addressing the challenges at each stage in the PMTCT cascade will provide incremental benefits in provision not only of cotrimoxazole prophylaxis, but also of other interventions along the PMTCT cascade.

## **10.6 RECOMMENDATIONS**

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### **10.6.1 Recommendations to ensure optimum provision of services at health centres**

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#### **10.6.1.1 Health care system financing**

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Government should consider increasing the budget allocation to Ministry of Health; there is need for Government funding of City of Harare services to avoid the latter's over-reliance on user fees.

Since user fees present the greatest barrier to ANC registration, City of Harare might consider reducing them or scraping them altogether. This should be carefully planned as discussed earlier in this chapter.

There is need for improvement in the management of donor funds; avoidance of duplication of funding (as recommended by the Paris Declaration) is important.

#### **10.6.1.2 Health care system staffing**

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There is need to ensure that adequate numbers of staff are recruited to ensure that health care centres run smoothly.

As qualified health care workers are more expensive to hire, there is need for task shifting as discussed in the main Discussion. Ministry of Health and Child Welfare have established a cadre called Primary Counsellor whose roles include pre and post-test counselling and adherence counselling. This cadre is not yet available in the City of Harare system; there is need to ensure that these positions are established.

#### **10.6.1.3 Staff training**

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Staff should be trained on good client relations. A system of management should be established to ensure that nurses provide professional and sympathetic services.

When new guidelines are introduced, there is need to ensure that training is cascaded down to the health care workers who are on the ground. This might involve training a group of trainers who will provide on-site training to all health care workers at each health care institution. Government might consider introducing a system where health care workers are not allowed to provide services unless they have received relevant training on new guidelines.

Health care workers at clinic pharmacies need to be trained on supply chain management.

There is need for regular Ministry of Health supportive visits to health care centres; these are important both to provide support and clarification on guidelines and for monitoring purposes.

#### **10.6.1.4 Enforcement of professional conduct among health care workers**

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There is need to develop and implement a system for rewarding health care workers who conduct themselves professionally and are conscious of patient rights. For example, the Government might consider introducing results-based financing to reward health care centres with good patient-centred outcomes. Similarly, there is need to develop and implement a system for identifying and disciplining health care workers who do not perform well or those who do not conduct themselves professionally.

#### **10.6.1.5 Integration of services**

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The Child Health Services Clinics (which provide well baby clinics and immunisations) might be integrated with HIV care services in order to 1) reduce time spent at the clinic through attendance of separate clinics; 2) ensure better implementation of guidelines to test all babies whose HIV exposure status is unknown, 3) reduce loss to follow-up as a result of referral to a different clinic, and 4) enable women to feel able to collect cotrimoxazole or ARV prescription refills without the fear of unwanted HIV disclosure which is experienced at the chronic diseases clinic. For this to work there is need to allow for confidential provision of services at these clinics.

Given that the chronic diseases clinic is viewed by attendees as an HIV clinic (making it difficult for women to collect prescription refills because of fear of unwanted HIV disclosure), Mbare Clinic might consider integrating the chronic diseases clinic with the general out-patients clinic.

#### **10.6.1.6 Review of cotrimoxazole prophylaxis guidelines**

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Travel post-delivery is common; there is need to amend guidelines to ensure provision of cotrimoxazole prophylaxis earlier than six weeks for the mother to take and start at six weeks.

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## **10.6.2 Recommendations to enable women to take up services along the PMTCT cascade**

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### **10.6.2.1 User fees**

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As stated above, City of Harare might consider reducing or removing user fees for ANC registration.

### **10.6.2.2 Improved education of patients/attendees**

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During consultation, nurses should ensure that patients/attendees are well educated:

- Patients/attendees should be taught about the meaning of an HIV diagnosis and available PMTCT services and services for the mother's own HIV Care. Messaging should ensure understanding of the fact that an HIV diagnosis does not mean impending death.
- Women should be made aware of the importance of the six-week visit, both for the mother and the baby (if HIV-exposed).
- Patients/attendees should be encouraged to ask questions where they are not clear (health care workers need to create an enabling environment for this).

### **10.6.2.3 Campaigns to improve male involvement in PMTCT programs**

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There is need to educate men about the importance of ANC registration.

Interventions to increase HIV testing and counselling among men are essential. Household testing and counselling might be adopted to increase uptake of HIV testing and male acceptability of HIV testing.

### **10.6.2.4 Social support for HIV positive women**

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Women should be encouraged to seek existing social support services which can help them deal with challenges related to living with HIV.

Health care systems might consider developing a system where community volunteers provide social support to HIV positive mothers. The volunteers can remind the HIV positive women to adhere to prescription visit schedules, support medication adherence, or link the women to HIV care services for their own health.



#### **10.6.2.5 Incentivising attendance of clinic visits**

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City of Harare might consider incentivising attendance of the six-week visit, e.g. through reduced consultation fees for all women seeking clinic services after the six-week postnatal period provided they can demonstrate attendance of the six-week visit.

City of Harare might also consider incentivising early ANC registration, e.g. by charging reduced user fees for early registrants.

#### **10.6.2.6 Follow-up of defaulters**

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Given the high mobile telephone density in Zimbabwe, City of Harare might consider introducing reminder text messaging for patients who have missed their appointments.

Related to this, given the belief by some women that the clinic does not attend to people who have missed their appointments, the clinic needs to develop and communicate a good system for re-booking missed appointments.

#### **10.6.2.7 Stigma reduction**

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There is need for continued education of communities and health care workers about the need for avoidance of HIV stigma.

Given the fact that studies that have evaluated the effectiveness of stigma-reduction interventions have not been rigorously done, there is need for carefully designed studies that evaluate the effectiveness of stigma-reduction strategies in the Zimbabwean context.

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## APPENDICES

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## APPENDIX 1: QUESTIONNAIRE AT TIME OF DELIVERY

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### Patient questionnaire for completion at the time of delivery

Thank you for consenting to take part in this study that will enable us to have a better understanding of the experiences of expecting mothers in this community. I am asking you to give your responses to the questions which follow. Some questions may make you feel uncomfortable or distressed. Obviously if this happens we will stop the interview if you would like us to. As far as possible please give me your honest answers.

Date of interview: \_\_\_\_\_ Clinic of delivery: \_\_\_\_\_

DDMMYYYY

Date baby was born: \_\_\_\_\_

DDMMYYYY

1. When were you born? /How old are you?

***Date of Birth:*** \_\_\_\_\_ ***or current age*** \_\_\_\_\_

***DDMMYYYY***

2. What is your religion?

- a. Roman Catholic
- b. Anglican
- c. Lutheran
- d. Methodist
- e. Baptist
- f. Presbyterian
- g. Apostolic
- h. Pentecostal
- i. Seventh Day Adventist
- j. Moslem
- k. African Traditional Religion
- l. Other (Specify) \_\_\_\_\_
- m. No religion

3. What is the highest level of education that you have completed?

- a. None
- b. Primary school only
- c. Forms 1 to 2
- d. Forms 3 to 4
- e. Forms 5 to 6
- f. Diploma/Certificate/Degree

4. ***FOR RURAL PARTICIPANTS ONLY:*** Think about the building in your home that is the most appealing. What material is it built of?

- a. Pole and dagga
- b. Wood
- c. Mud bricks
- d. Cement blocks
- e. Stones
- f. Other (Specify): \_\_\_\_\_

- i. **For Mbare Participants:**How many rooms does the house you live in have, excluding the toilet and bathroom?
    1. Specify:\_\_\_\_\_
5. Are you staying here as?
  - a. House owner
  - b. Lodger
  - c. Family member
  - d. Other (Specify):\_\_\_\_\_
    - i. How many people live in your household? **Specify:** \_\_\_\_\_
6. What type of sewage disposal system do you use?
  - a. Flush Bowl System
  - b. Our own Blair toilet
  - c. Neighbour's Blair toilet
  - d. Bush
  - e. Pit
  - f. Other (Specify):\_\_\_\_\_
7. What source of drinking water do you use in your house? (choose one main source)
  - a. Tapped communal
  - b. Own tap
  - c. Own borehole
  - d. Communal borehole
  - e. Unprotected well
  - f. Protected well
  - g. Stream/river
  - h. Other (Specify)\_\_\_\_\_
8. In the last week, has an adult in your house skipped a meal or eaten less in order for there to be enough food for the children?
  - a. Yes
  - b. No
9. In the last week, have you had to go an entire day without eating because there was no food in your household?
  - a. Yes
  - b. No
10. Approximately how much money do you earn/source each month in US dollars?
  - a. I don't earn any money
  - b. I earn \$\_\_\_\_\_
11. Are you currently married?
  - a. Yes, I am currently married
  - b. No, I am divorced **go to 13**
  - c. No, I am widowed **go to 13**
  - d. No, I have never been married **go to 13**
12. Approximately how much money does your partner earn/source each month in US dollars?
  - a. He does not earn any income
  - b. He earns \$\_\_\_\_\_
13. Are you financially dependent on anyone?
  - a. Yes
  - b. No **go to 14**
    - i. Who are you financially dependant on? **Mark all that apply.**
      1. Husband/Partner
      2. Parents
      3. Mother/Father in law
      4. Brother/sister
      5. Bother/sister in law
      6. Someone else (Specify)\_\_\_\_\_
14. How many children have you had in your life so far? (Specify)\_\_\_\_\_

15. Did any of your children die?

a. Yes

b. No *go to 16*

i. How many children died in total? Specify) \_\_\_\_\_

ii. How old was/were the child/children when they died? (*Specify*)

*Child 1=most recent death:*

*Child 1* \_\_\_\_\_ *years/months*      *Child 2* \_\_\_\_\_ *years/months*

*Child 3* \_\_\_\_\_ *years/months*

*Other children who died:*

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*For age greater than two years use years and months for age 24 months and younger*

16. Now I am going to ask you about your children who are alive. We want to know how old they are and what their general health status is.

Child	Age	Health Status
		<input type="checkbox"/> Healthy <input type="checkbox"/> Frequently ill
		<input type="checkbox"/> Healthy <input type="checkbox"/> Frequently ill
		<input type="checkbox"/> Healthy <input type="checkbox"/> Frequently ill
		<input type="checkbox"/> Healthy <input type="checkbox"/> Frequently ill

*Other children:*

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*For age greater than two years use years and months for age 24 months and younger*

Child 1=the most recent delivery ie the new born baby

17. Combined with question 16.

18. Have you had any miscarriages?

a. Yes

b. No *go to 19*

i. How many miscarriages have you had? (*Specify*) \_\_\_\_\_



- ii. How far gone with the pregnancy were you when you miscarried? *Specify in number of weeks in each box as applicable*

Miscarriage 1	
Miscarriage 2	
Miscarriage 3	
Miscarriage 4	
Miscarriage 5	

*Other miscarriages:*

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For some women being pregnant may be a joyful experience but for some it can be difficult.

19. For your last pregnancy, at what point did you discover that you were pregnant?
- In the first month
  - In the second month
  - In the third month
  - More than three months into pregnancy
  - I don't know
20. How did you discover that you were pregnant? *Mark all that apply*
- I missed my monthly menstrual period
  - Symptoms like nausea and vomiting (or other symptoms)
  - I bought a pregnancy test kit and tested myself at home
  - A health care worker gave me a pregnancy test or confirmed that I was pregnant
    - What is the date of your last menstrual period? *Interviewer to verify this date with the patient records*
      - Specify: \_\_\_\_ / \_\_\_\_ / \_\_\_\_  
DDMMMYYYY
21. Did you plan to get pregnant?
- Yes
  - No *go to 22*
    - Were you on a family planning method at the time you became pregnant?
      - Yes
      - No *go to 22*
    - What family planning method were you using?
      - Pill
      - Injectable contraceptive
      - IUD
      - Implant
      - Other (Specify): \_\_\_\_\_
22. How did you feel when you discovered that you were pregnant?
- Happy *go to 23*
  - Troubled
  - Neither happy nor troubled *go to 23*
    - Why were you troubled? *Mark all that apply*
      - I was worried about the financial burden of having a new baby
      - I just did not want to have another baby

3. I was worried about my health
  4. I was worried about the health of the baby
  5. Other (Specify): \_\_\_\_\_
23. Did you seek antenatal care after you discovered you were pregnant?
- a. Yes **go to 24**
  - b. No
    - i. Why did you not seek antenatal care?
      1. I had no money
      2. I did not think it was important
      3. My husband/mother in law/other family member did not want me to (Specify the family member): \_\_\_\_\_
      4. My religion does not allow me to  
Other: Specify \_\_\_\_\_ **to go 33**

24. Where did you seek antenatal care?
- a. Local clinic
    - i. At this clinic (Name of clinic)
    - ii. At another clinic (Specify) \_\_\_\_\_
  - b. Local hospital
  - c. Private doctor
  - d. Other  
Specify: \_\_\_\_\_

25. When did you first seek antenatal care? Specify: \_\_\_\_\_  
DDMMMYYYY

***Interviewer to verify this date with the participant records***

26. Deleted.
27. Did you keep visiting this health care centre (mentioned in 24a) after your first visit?
- a. Yes **go to 28**
  - b. No
    - i. Did you visit another health care centre instead?
      1. Yes **go to iii**
      2. No **go to a**
        - a. Why did you not have return clinic visits for antenatal care?
          - i. I had no money
          - ii. I did not think it was important
          - iii. My husband/mother in law/other family member did not want me to
            1. Specify the family member: \_\_\_\_\_
          - iv. My religion does not allow me to
          - v. Other: Specify \_\_\_\_\_  
**go to 30**
    - ii. Deleted
    - iii. Why did you change health facilities?
      1. I had relocated
      2. I temporarily moved to be closer to my mother/another relative while I was pregnant
      3. I did not like the care I was getting at that clinic
      4. I could not afford the care I was getting at that health care facility
      5. Other (Specify): \_\_\_\_\_

28. Deleted.

29. Deleted.

It is common practise for women to get tested for some diseases or conditions, including sexually transmitted infections when they are pregnant. I would like you to tell me if you got tested for the following conditions.

30. Were you tested for high blood pressure? (Here we are talking about a procedure in which the health care worker places a cuff around your upper arm, applies pressure to it and then reads your blood pressure).

a. Yes

b. No **go to 31**

**DELETED 30 i-iv**

31. Were you tested for high blood sugar level? (Here we are talking about a procedure in which the health care worker would have asked you to give a blood or urine sample that could be tested for diabetes).

a. Yes

b. No **go to 32**

**Deleted 31i-iv**

32. Were you tested for syphilis? (here we are talking about a procedure in which the health care worker would have collected blood that would be sent for syphilis testing)

a. Yes

b. No **go to 33**

**If yes**

i. At which month were you tested for syphilis?

1. 1<sup>st</sup> Month

2. 2<sup>nd</sup> Month

3. 3<sup>rd</sup> Month

4. 4<sup>th</sup> Month

5. 5<sup>th</sup> Month

6. 6<sup>th</sup> Month

7. 7<sup>th</sup> Month

8. 8<sup>th</sup> Month

9. 9<sup>th</sup> Month

ii. What was the outcome of the test?

1. I tested negative for syphilis **go to 33**

2. I tested positive for syphilis

3. I did not receive my results **go to 33**

**DELETED 33iii-vib**

33. Have you been tested for HIV?

a. Yes **go to ii**

b. No **go to i**

i. Why have you not been tested for HIV?

1. I have been not offered the test **go to 34**

2. I refused the test **go to 34**

3. Other reason (Specify) \_\_\_\_\_ **go to 34**

ii. When were you tested for HIV? **Mark all that apply**

1. During 1<sup>st</sup> Month of last pregnancy (for your newest baby)

2. During 2<sup>nd</sup> Month of last pregnancy, (for your newest baby)

3. During 3<sup>rd</sup> Month of last pregnancy, (for your newest baby)

4. During 4<sup>th</sup> Month of last pregnancy, (for your newest baby)

5. During 5<sup>th</sup> Month of last pregnancy, (for your newest baby)

6. During 6<sup>th</sup> Month of last pregnancy, (for your newest baby)
  7. During 7<sup>th</sup> Month of last pregnancy, (for your newest baby)
  8. During 8<sup>th</sup> Month of last pregnancy, (for your newest baby)
  9. During 9<sup>th</sup> Month of last pregnancy, (for your newest baby)
  10. Before I got pregnant (last pregnancy), (for your newest baby)
  11. I don't remember
- iii. Where was your most recent HIV test?
1. Clinic
    - a. This Clinic (Name of Clinic)
    - b. Another Clinic (Specify)
  2. Hospital
  3. VCT Centre
  4. Other: Specify \_\_\_\_\_
- iv. What was the outcome of the test?
1. I tested HIV positive
  2. I tested HIV negative **go to 34**
  3. I did not receive my results
  4. I do not want to reveal my status to the interviewer **go to 34**
- v. Are you taking antiretroviral drugs for the treatment of HIV? (*interviewer please note this is different from the More Efficacious Regimen (MER) for PMTCT*)
1. Yes
  2. No **go to vi**
    - a. When did you start taking the antiretroviral drugs?
      - i. Before I got pregnant
      - ii. When I was pregnant, before I was 8 months pregnant
      - iii. When I was pregnant, after 8 months of pregnancy
      - iv. I do not remember
    - b. Do you take the antiretroviral drugs as prescribed?
      - i. Never
      - ii. Sometimes
      - iii. Most of the time
      - iv. All the time
- Go to xii**
- vi. Did you receive the antiretroviral medicine AZT (Zidovudine) that you were to take twice daily from when you were about seven months pregnant?
1. Yes
  2. No **go to viii**
- Check with Patient Medical Card**
- vii. Did you take the tablets twice daily as instructed?
1. Never **go to a**
  2. Sometimes **go to a**
  3. Most of the time **go to a**
  4. All the time **go to viii**
    - a. What prevented you from taking them as instructed?
      - i. I forgot
      - ii. I lost the tablets
      - iii. My husband/mother in law or other relative did not allow me to (Specify) \_\_\_\_\_
      - iv. My religion does not allow me
      - v. I was not able to collect some of my tablets from the clinic

- vi. Other (specify)\_\_\_\_\_
- viii. Did you receive nevirapine (medicine that reduces the chances of transmitting HIV to your baby) that you were supposed to take at the beginning of your labour pains?
1. Yes
  2. No **go to xi**
- ix. Did you take the tablets as instructed?
1. Yes **go to xii**
  2. No
- x. What prevented you from taking the tablets as instructed?
1. I forgot
  2. I lost the tablets
  3. My husband/mother in law or other relative did not allow me to (Specify)\_\_\_\_\_
  4. My religion does not allow me
  5. I didn't want others to know that I was taking tablets
  6. Other (Specify):\_\_\_\_\_ **go to viii**
- xi. Why did you not receive treatment?
1. I had no money
  2. I refused the treatment
  3. My husband/mother in law/ other family member prevented me from taking it (**Specify which family member**)\_\_\_\_\_
  4. No treatment/medicine was available at the clinic
  5. Other reason (Specify):\_\_\_\_\_

**Interviewer to check the patient medical records to see what was prescribed to the baby and complete the following information.**

**Mark all that apply:**

- i. **Single dose nevirapine 2mg/kg**
  - ii. **AZT 4mg/kg 12 hourly for 7 days**
  - iii. **AZT 4mg/kg 12 hourly for 28 days**
- xii. **Interviewer to read as applicable:**
1. **If baby was given any of the above medicines:** I see on your card that your baby received medicine that helps prevent acquisition of HIV soon after delivery **go to b**
  2. **If not given any medicine:** I see on your card that your baby did not receive medicine that helps prevent acquisition of HIV soon after delivery **go to xiii**
    - a. **Removed.**
    - b. How many hours after you gave birth was the baby given medicine?
      - i. Within 24 hours
      - ii. Within 48 hours
      - iii. Within 72 hours
      - iv. I do not remember**Go to xiv**
- xiii. Why did the baby not receive the medicine?
1. It was not offered
  2. I refused
  3. I do not know
  4. Other (Specify)\_\_\_\_\_

- xiv. Did you tell anyone about your HIV status after you tested positive for HIV?
  - 1. Yes
  - 2. No **go to 34**
- xv. Who did you tell? **Mark all that apply.**
  - 1. Husband/partner
  - 2. Friend
  - 3. Mother
  - 4. Sister
  - 5. Brother
  - 6. Aunt
  - 7. Sister in Law
  - 8. Other (Specify) \_\_\_\_\_
- xvi. Deleted.
- 34. Has your current or most recent partner been tested for HIV?
  - 1. Yes
  - 2. No **go to 35**
  - 3. I don't know **go to 35**
- ii. What was the result of the test?
  - 1. Positive
  - 2. Negative
  - 3. He did not collect his result
  - 4. He did not tell me

Now we would like to ask you about previous HIV tests you have taken.

- 35. Before this pregnancy, have you ever had any HIV tests?
    - a. Yes
    - b. No **go to 36**
      - i. How many times were you tested?
        - 1. Once
        - 2. Twice
        - 3. Three times
        - 4. Four times
        - 5. Five times
        - 6. More than five times
      - ii. What motivated you to do the last HIV test before the last pregnancy? **Mark all that apply**
        - 1. I was pregnant
        - 2. I was not feeling well
        - 3. I just wanted to know my HIV status
        - 4. There is someone/there are people who encouraged me to get tested
        - 5. It was a requirement for work/insurance (Specify)\_\_\_\_\_
        - 6. My husband/partner and I decided to get tested before we got married or started having sex
        - 7. Other reason (Specify) \_\_\_\_\_
      - iii. How much time had elapsed between the last HIV test you took (before this pregnancy) and the test you took during this pregnancy? **Specify in number of years or months**\_\_\_\_\_
- OR, IF NOT TESTED DURING LAST PREGNANCY:**

How long ago was the last HIV test you took?

*Specify in number of years* \_\_\_\_\_

iv. What was the outcome of the last HIV test (before the one you took during this pregnancy?

1. I tested HIV positive
2. I tested HIV negative
3. I did not receive my results

36. ***For patients who accessed ANC services ie answered yes to question 23:*** While you were still pregnant did you fall sick and visit the clinic between your scheduled antenatal visits to seek treatment?

a. Yes ***go to ii***

b. No ***go to 37 if HIV positive, otherwise go to 40***

i. For those who did not seek antenatal care: While you were pregnant did you fall sick and visit the clinic to seek treatment?

ii. How many times did you seek the medical care?

1. Once
2. Twice
3. Three times
4. Four times
5. More than four times
6. I do not remember

Now I want you to think about each visit you made during your last pregnancy in which you had come to seek treatment. For each visit we want to know what you were suffering from and how far gone in your pregnancy you were.

Visit	What were you suffering from?	How far gone was your pregnancy?
	<input type="checkbox"/> Headache <input type="checkbox"/> Malaria <input type="checkbox"/> Backache <input type="checkbox"/> Stomach Problems <input type="checkbox"/> Injury (accident, domestic violence, physical violence) <input type="checkbox"/> General unwellness <input type="checkbox"/> Other problem (specify): _____	<input type="checkbox"/> Less than 3 months pregnant <input type="checkbox"/> Between 3 and 6 months pregnant <input type="checkbox"/> More than 6 months pregnant
	<input type="checkbox"/> Headache <input type="checkbox"/> Malaria <input type="checkbox"/> Backache <input type="checkbox"/> Stomach Problems <input type="checkbox"/> Injury (accident, domestic violence, physical violence) <input type="checkbox"/> General unwellness <input type="checkbox"/> Other problem (specify): _____	<input type="checkbox"/> Less than 3 months pregnant <input type="checkbox"/> Between 3 and 6 months pregnant <input type="checkbox"/> More than 6 months pregnant
	<input type="checkbox"/> Headache <input type="checkbox"/> Malaria <input type="checkbox"/> Backache <input type="checkbox"/> Stomach Problems <input type="checkbox"/> Injury (accident, domestic violence, physical violence) <input type="checkbox"/> General unwellness <input type="checkbox"/> Other problem (specify): _____	<input type="checkbox"/> Less than 3 months pregnant <input type="checkbox"/> Between 3 and 6 months pregnant <input type="checkbox"/> More than 6 months pregnant
	<input type="checkbox"/> Headache <input type="checkbox"/> Malaria	<input type="checkbox"/> Less than 3 months pregnant

	<input type="checkbox"/> Backache <input type="checkbox"/> Stomach Problems <input type="checkbox"/> Injury (accident, domestic violence, physical violence) <input type="checkbox"/> General unwellness <input type="checkbox"/> Other problem (specify):_____	<input type="checkbox"/> Between 3 and 6 months pregnant <input type="checkbox"/> More than 6 months pregnant
	<input type="checkbox"/> Headache <input type="checkbox"/> Malaria <input type="checkbox"/> Backache <input type="checkbox"/> Stomach Problems <input type="checkbox"/> Injury (accident, domestic violence, physical violence) <input type="checkbox"/> General unwellness <input type="checkbox"/> Other problem (specify):_____	<input type="checkbox"/> Less than 3 months pregnant <input type="checkbox"/> Between 3 and 6 months pregnant <input type="checkbox"/> More than 6 months pregnant
	<input type="checkbox"/> Headache <input type="checkbox"/> Malaria <input type="checkbox"/> Backache <input type="checkbox"/> Stomach Problems <input type="checkbox"/> Injury (accident, domestic violence, physical violence) <input type="checkbox"/> General unwellness <input type="checkbox"/> Other problem (specify):_____	<input type="checkbox"/> Less than 3 months pregnant <input type="checkbox"/> Between 3 and 6 months pregnant <input type="checkbox"/> More than 6 months pregnant
	<input type="checkbox"/> Headache <input type="checkbox"/> Malaria <input type="checkbox"/> Backache <input type="checkbox"/> Stomach Problems <input type="checkbox"/> Injury (accident, domestic violence, physical violence) <input type="checkbox"/> General unwellness <input type="checkbox"/> Other problem (specify):_____	<input type="checkbox"/> Less than 3 months pregnant <input type="checkbox"/> Between 3 and 6 months pregnant <input type="checkbox"/> More than 6 months pregnant

iii. I am now going to ask you about tests that may have been carried out when you made visits to seek treatment. We want to know whether these tests were done.

1. Were you tested for high blood pressure? (Here we are talking about a procedure in which the health care worker places a cuff around your upper arm, applies pressure to it and then reads your bold pressure).
  - a. Yes
  - b. No
2. Were you tested for high blood sugar level? (Here we are talking about a procedure in which the health care worker would have asked you to give a blood or urine sample that could be tested for diabetes).
  - a. Yes
  - b. No
3. Were you tested for syphilis? (*here we are talking about a procedure in which the health care worker would have collected blood that would be sent for syphilis testing*)
  - a. Yes
  - b. No go to 37 if HIV positive, otherwise go to 40
    - i. At which month of your pregnancy were you tested for syphilis?
      1. 1<sup>st</sup> Month
      2. 2<sup>nd</sup> Month



3. 3<sup>rd</sup> Month
4. 4<sup>th</sup> Month
5. 5<sup>th</sup> Month
6. 6<sup>th</sup> Month
7. 7<sup>th</sup> Month
8. 8<sup>th</sup> Month
9. 9<sup>th</sup> Month

- ii. What was the outcome of the test?
  1. I tested negative for syphilis **go to 33**
  2. I tested positive for syphilis
  3. I did not receive my results **go to 33**

**Questions 37 to 39 only for those who are HIV positive**

37. Have you been told where you can access HIV related care?
  - a. Yes
  - b. No **go to 38**
    - i. Have you been told when you should seek this care
      1. Yes
      2. No **go to 38**
    - ii. Do you think you are going to seek the care as advised?
      1. Yes **go to 38**
      2. No
      3. I have already sought care **go to 38**
    - iii. Why do you think you are not going to seek the care?
      1. I do not have money
      2. My religion does not allow me
      3. My husband/mother-in-law/other relative will not allow me
        - a. Specify which relative: \_\_\_\_\_
      4. People may stigmatise me if they see me seeking HIV related care
      5. Other reason
38. Do you think your baby is at risk of contracting HIV from you?
  - a. Yes
  - b. No
39. Have you been given any information about how to reduce your risks of transmitting HIV to your baby by the clinic staff?
  - a. Yes
  - b. No **go to 40**
    - i. What information were you given?

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Are you planning to bring your baby to the six weeks baby clinic?

- c. Yes **end of form**
  - d. No
    - i. Why do you not want to bring your baby to the six week visit?
      1. I do not think it is important
      2. It is too far to travel to the clinic
      3. I will go to another clinic
      4. It is too expensive to travel to the clinic
      5. I will be too busy to get time to come to the clinic
      6. My religion does not allow me
      7. My husband or mother-in law or other relative does not allow it  
(Specify) \_\_\_\_\_
      8. Other reason (Specify) \_\_\_\_\_
- End of form**



## APPENDIX 2: QUESTIONNAIRE AT SIX WEEKS

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### Patient Questionnaire for Completion at Six weeks

Thank you for consenting to take part in this study that will enable us to have a better understanding of the experiences of HIV positive women and their newborn babies. I will ask you to give your responses to the questions which follow. Some questions may make you feel uncomfortable or distressed. Obviously if this happens we can stop the interview. As far as possible please give me your honest answers.

*Sections in italics are not to be asked of the participant but are directed at the nurse-interviewer.*

Date of interview: \_\_\_\_\_

DDMMYYYY

1. Since the delivery of your baby, how has your health been?
  - a. I feel as well as any woman who has just had a baby *go to 4*
  - b. I have been feeling generally unwell
  - c. I have been very unwell
2. Have you sought treatment?
  - a. Yes
  - b. No *go to 3*
    - i. Where have you sought the treatment?
      1. Local clinic
        - a. This Clinic (Specify name) \_\_\_\_\_
        - b. Another Clinic (Specify name) \_\_\_\_\_
      2. Local Hospital
      3. Private clinic/doctor/hospital
      4. Traditional healer
      5. Other (Specify) \_\_\_\_\_
    - ii. Were you told what you were suffering from?
      1. Yes
      2. No *go to 4*
        - a. Is the illness HIV-related?
          - i. Yes *go to 4*
          - ii. No *go to 4*
          - iii. I do not know *go to 4*
3. Why have you not sought treatment?
  - a. I thought I would get better
  - b. I have no money
  - c. My religion does not allow me
  - d. My husband/mother-in-law/other family member does not allow me  
Specify family member: \_\_\_\_\_
  - e. Other reason
4. *Does the mother have a hand-held medical record from the local clinic or hospital?*
  - a. Yes
  - b. No *go to 5*
    - i. *Has she been examined to determine WHO clinical disease stage?*
      1. Yes
      2. No
    - ii. *Has she been referred for further HIV care eg clinical staging, CD4+ counts and clinical staging?*
      1. Yes
      2. No

5. Are you aware of where you should seek HIV-related care for yourself?
  - a. At the local clinic
  - b. At the local hospital
  - c. At the private doctor/private hospital
  - d. At the traditional healer's
  - e. At the religious healer's
  - f. Other (Specify)\_\_\_\_\_
  - g. I am not aware of where I should seek care
6. Are you aware of when you should seek that care?
  - a. As soon as possible
  - b. When I start feeling unwell
  - c. I do not know when I should seek care
7. Will you seek care?
  - a. Yes **go to 9**
  - b. No
8. Why will you not seek care?
  - a. I cannot afford the money
  - b. I do not believe the illness could be treated by medical personnel
  - c. My religion does not allow me to seek care
  - d. My husband/mother-in-law/other family member will not allow me to  
Specify which family member: \_\_\_\_\_
  - e. Other (Specify):\_\_\_\_\_
9. From the time the baby was born, in general, has s/he been feeling well?
  - a. As well as any baby **go to 12**
  - b. The baby has generally been unwell
  - c. The baby has been very unwell
10. Have you sought treatment for the baby?
  - a. Yes
  - b. No **go to 11**

**If yes**

- i. Where did you seek the treatment?
  1. Local Clinic
    - a. This Clinic (Specify name)\_\_\_\_\_
    - b. Another Clinic (Specify name)\_\_\_\_\_
  2. Local Hospital
  3. Private clinic/doctor/hospital
  4. Traditional healer
  5. Other (Specify)\_\_\_\_\_
- ii. Were you told what was wrong with the baby?
  1. Yes
  2. No **go to 12**

**If yes**

- iii. Was the baby's illness HIV related?
    1. Yes
    2. No
    3. I do not know
- Go to 12**

11. Why did you not seek medical care for the baby? **Mark all that apply**
  - a. I did not know what to do
  - b. I did not have the money to seek care
  - c. I did not believe the illness could be treated by medical personnel
  - d. I thought it would get better

- e. My religion does not allow me to
- f. My husband/mother-in-law/other family member did not allow me to  
Specify which family member\_\_\_\_\_
- g. Other reason
- 12. Were you given any medicine for the child today?
  - a. Yes
  - b. No
- 13. *Ask for the child's hand-held medical record from the local clinic or hospital. Was the infant initiated on cotrimoxazole prophylaxis at this visit? Care should be taken to differentiate between cotrimoxazole given for prophylaxis and that given for treatment of infections.*
  - a. *Yes*
  - b. *No go to 14*
    - i. *How much cotrimoxazole was dispensed? Specify in millilitres\_\_\_\_\_*
    - ii. Were you told when you are return to collect additional supplies of this medicine called cotrimoxazole?
      - 1. Yes
      - 2. No
    - iii. Are you going to be able to complete the return visit to collect more cotrimoxazole?
      - 1. Yes *end of form*
      - 2. No
        - a. What will prevent you from returning to collect more cotrimoxazole supplies?
          - i. I do not believe it will help the baby
          - ii. It is too expensive to come to the clinic
          - iii. My husband/mother-in-law/other family member will not allow me to. Specify which family member\_\_\_\_\_
          - iv. My religion does not allow me to
          - v. I will not have time to return
          - vi. Other (Specify)\_\_\_\_\_ *end of form*
- 14. Were you told that the baby should take some medicine called cotrimoxazole on a daily basis?
  - i. Yes
  - ii. No *go to 16*
- 15. Why was the medicine not given to you?
  - i. It was not in stock
  - ii. I refused it
  - iii. I don't know
- 16. *Immediately after the interview the nurse who saw the mother and infant should be asked why the baby was not given cotrimoxazole. The reason should be documented as below:*
  - a. *Out of stock*
  - b. *Overlooked by caregiver (nurse)*
  - c. *Refusal by mother/caregiver*
  - d. *Other (Specify):\_\_\_\_\_ end of form*

### APPENDIX 3: QUESTIONNAIRE FOR CLINIC RECORD STUDY

#### STUDY OF SIX WEEKS ATTENDANCE AT EDITH OPPERMAN CLINIC (MBARE)

Name	Date Of Birth	Date of delivery	ANC Booking Status	HIV status	Area of residence	6 weeks visit conducted <i>(Enter date at each of 5,6,7 and 8 weeks, then tick if visit was attended)</i>	Tick if 6-weeks visit <i>NOT</i> attended
			<input type="checkbox"/> Booked <input type="checkbox"/> Unbooked	<input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Unknown		5 weeks: ____ - ____ - ____ <input type="checkbox"/> 6 weeks: ____ - ____ - ____ <input type="checkbox"/> 7 weeks: ____ - ____ - ____ <input type="checkbox"/> 8 weeks: ____ - ____ - ____ <input type="checkbox"/>	
			<input type="checkbox"/> Booked <input type="checkbox"/> Unbooked	<input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Unknown		5 weeks: ____ - ____ - ____ <input type="checkbox"/> 6 weeks: ____ - ____ - ____ <input type="checkbox"/> 7 weeks: ____ - ____ - ____ <input type="checkbox"/> 8 weeks: ____ - ____ - ____ <input type="checkbox"/>	
			<input type="checkbox"/> Booked <input type="checkbox"/> Unbooked	<input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Unknown		5 weeks: ____ - ____ - ____ <input type="checkbox"/> 6 weeks: ____ - ____ - ____ <input type="checkbox"/> 7 weeks: ____ - ____ - ____ <input type="checkbox"/> 8 weeks: ____ - ____ - ____ <input type="checkbox"/>	
			<input type="checkbox"/> Booked <input type="checkbox"/> Unbooked	<input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Unknown		5 weeks: ____ - ____ - ____ <input type="checkbox"/> 6 weeks: ____ - ____ - ____ <input type="checkbox"/> 7 weeks: ____ - ____ - ____ <input type="checkbox"/> 8 weeks: ____ - ____ - ____ <input type="checkbox"/>	
			<input type="checkbox"/> Booked <input type="checkbox"/> Unbooked	<input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Unknown		5 weeks: ____ - ____ - ____ <input type="checkbox"/> 6 weeks: ____ - ____ - ____ <input type="checkbox"/> 7 weeks: ____ - ____ - ____ <input type="checkbox"/> 8 weeks: ____ - ____ - ____ <input type="checkbox"/>	

Staff Initials/Date: \_\_\_\_\_

## APPENDIX 4: IN-DEPTH INTERVIEW GUIDES

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### Interview guide for participants who did not register for ANC or delayed registering for ANC

Thank you for participating in this study. We are trying to understand what factors affect women decisions to seek health care when they are pregnant. Our discussion today will be around this topic. Please try where possible to answer as fully as you can. It is possible that some of the questions might cause you to feel uncomfortable. Obviously if this happens we can stop the interview. As far as possible please give me your honest answers –the information you provide will be combined with information provided by many other women and so it will not be possible for your views or experiences to be traced back to you. We value the information you will give us because it may help improve the way health care services are provided to pregnant women.

1. Where do you live? **(Probe how far away from Edith Opperman the house is in terms of distance, whether it is a walkable distance)**
2. Is Edith Opperman the nearest clinic to your house that offers maternity services? **(Probe: if there are nearer clinics than Edith Opperman why not go to those instead?)**
3. Do you know why women are asked to attend for antenatal care before they deliver?
4. Do you know what specific benefits antenatal care can provide?
5. In your opinion, is registering for ante-natal care (ANC) important? **(Probe for reasons)**
6. At what stage in her pregnancy are women advised to register for ANC?
7. What services are offered to HIV positive women when they are pregnant?
8. Do you think many women in Mbare are aware of the need to register for ANC? **(Probe: Do they know why they should register /why ANC is important? Are women aware of when they should register? ).**
9. In our study we have noticed that many women either delay registering for ANC or do not register at all. Why do you think this is? **(Probe: financial concerns, mother-in-law resistance, transport concerns, people don't think important, care not recognised to be beneficial, reluctant to test for HIV/high blood pressure, diabetes etc).**
10. Do you feel that the community you come from is generally in support of health care services that are offered to pregnant women at health care centres?
11. Do you feel that your family is in support of health care services that are offered to pregnant women at health care centres?

**For HIV negative women who did not register for ANC/delayed registering**

12. When you answered the questionnaire previously you mentioned that you did not register for ANC/or delayed registering, meaning you registered after 24 weeks of pregnancy. Why did you not register earlier/delay registering?
13. What do you think could be done to encourage women to register for ANC earlier in their pregnancy?
14. Do you have any questions or are there other things which are related to this topic that feel might help us understand these issues better?

**For HIV positive women who did not register for ANC/delayed registering**

8. When you answered **the questionnaire previously you mentioned** that you did not register for ANC/or delayed registering, meaning you registered after 24 weeks of pregnancy. Why did you not register earlier/delay registering?
9. When was the first time you were told you are HIV positive?
10. Are you currently receiving any HIV-related care? (**Probe: has disease stage been assessed; CD4 count; WHO staging, commencement on ART/CTX; TB screening /treatment; support group referral**)
11. In our study we were told by some HIV positive women that they chose not to disclose their HIV status to the nurses at the time of delivery. Why do you think this might be?
12. If applicable: Were you asked about your HIV status at the time you came for delivery
13. What do you think could be done to encourage HIV positive women to disclose their status to the nurses at the time of delivery?
14. Do you have any questions or are there other things which are related to this topic that you feel might help us understand these issues better?



## Interview guide for participants who did not complete their six weeks visit

### English Version

Thank you for participating in this study. We are trying to understand what factors affect women decisions to seek health care for themselves and their new babies. Our discussion today will be around this topic. Please try where possible to answer as fully as you can. It is possible that some of the questions might cause you to feel uncomfortable. Obviously if this happens we can stop the interview. As far as possible please give me your honest answers – the information you provide will be combined with information provided by many other women and so it will not be possible for your views or experiences to be traced back to you. We value the information you will give us because it may help improve the way health care services are provided to women who have just delivered their babies.

1. How old is your baby now? **Or** When was the baby born?
2. Where did you deliver the baby (clinic, hospital or at home)?
3. When you were discharged from hospital/clinic at the time of delivery, were you told when you were supposed to visit the clinic/hospital again? **(Probe which clinic/hospital was she told to visit; was the visit for the benefit of the mother of the baby; what would be the purpose of the visit)**
4. Did you visit the clinic as you per appointment? **(Probe for reasons if not. If she visited the clinic: What sort of help/services were offered? (Probe for services offered to the mother and also to the baby)**
5. Do you know why women are asked to attend a clinic visit when their baby is six weeks old?
6. Do you feel that the community you come from is generally in support of baby clinic visits?
7. Do you feel that your family is generally in support of baby clinic visits?
8. From our records, it appears that you did not attend the six weeks visit. Is this correct? **(Probe for reasons of non-attendance).**
9. Have you taken the baby to other baby clinics? **(Probe for when the baby was taken to the baby clinic, and whether the baby has received the appropriate immunization)**

### If the woman has attended the six weeks visit or other baby clinics

10. Is there any medicine that the baby was given when you attended the six weeks visit/baby clinic? (If given probe for: what is the name of the medicine; how much (in terms of quantity) it was, how was it supposed to be given, for how long was the baby supposed to take it)
11. **If baby was initiated on cotrimoxazole prophylaxis:** Were you told why you were supposed to give cotrimoxazole to the baby?
12. Were you told to come back for additional supplies of the medicine called cotrimoxazole?

13. Did you go back to the clinic to ask for additional supplies of cotrimoxazole?
14. What has been your experience in giving cotrimoxazole at home?
15. Are you always able to give the medicine at the right time? (**Probe for challenges, probe for what has worked well to ensure adherence**)
16. Do you think mothers or caregivers in general would find it easy to keep giving cotrimoxazole for a long time? (**Probe for reasons**)
17. What can be done to ensure the continued provision of cotrimoxazole to babies?
18. Do you have any questions or are there other things which are related to this topic that you feel might help us understand these issues better?

**If the woman has never taken the baby to the clinic/if cotrimoxazole prophylaxis was not given**

7. Are you aware that it is strongly recommended that babies born to HIV infected women take the medicine called cotrimoxazole to protect from diseases? (**If yes, probe for reasons why she has not tried to have her child given cotrimoxazole**).
8. What do you think should be done to help mothers/care givers to seek the appropriate care for their babies at health care institutions?
9. Do you have any questions or are there other things which are related to this topic that you feel might help us understand these issues better?

### Interview Guide for in-depth medication adherence interviews

Thank you for participating in this study that seeks to understand the experiences of HIV positive mothers who have just had new babies. Our discussion will be around this topic and I will ask you to give me your full responses. Some of the questions may cause you to feel distressed. Obviously if this happens we can stop the interview. As far as possible please give me your honest answers.

1. Where do you live?
2. Who do you live with? (*Probing: Is she married (if so, how long has she been married)? Does she live with extended family? Does she have other children besides the baby (if so how old are they)?*)
3. When did you have the baby – *how many days / weeks ago?*
4. Do you feel you have gone back to your old self or are you still feeling like you have just had a baby? (*Probing: Has she recovered her strength, is she back to doing the same chores she did before she had the baby?*)
5. You have been diagnosed as HIV infected. What does that mean to you? How do you feel about it? Were you surprised by the result? Have you been tested for HIV before the last pregnancy? Have you had any symptoms that might lead you to believe you were HIV infected? Have you told your partner? Has he tested?
6. Are you aware of the care that is due to HIV infected people? Have you accessed any HIV related care? *Probing: Has she had a CD4 count? How she got to know of the services/care. Why she has not accessed care (if applicable).*
7. What is your understanding of the possible effects of your HIV infection on the baby? *Probing: How she came to that understanding.*
8. Do you feel able to protect your baby from HIV? What can you do to help protect your baby? What advice have you been given regarding feeding your baby? do you feel able to follow these instructions?
9. The baby has been placed on cotrimoxazole. Do you understand why s/he should get that medicine? Do you think it is important for the baby to take the medicine on a daily basis?
10. Are there any challenges in ensuring that the baby takes cotrimoxazole on a daily basis as prescribed? *Probing: Any problems with giving the medicine daily. Any problems with getting uninterrupted supplies of cotrimoxazole?*
11. Is there any help you get from family or friends in ensuring that the baby remains on cotrimoxazole? *Probing: Is husband/partner/mother-in-law (if applicable) supportive*
12. Are you aware of any additional HIV-related medical care that your baby should receive? *Probing: What is the source of the knowledge? Details of times when the care processes are due. Does she intend to ensure that baby gets the care. Is she aware that at some point the baby should get tested for HIV? Is so at what time point?*
13. Do you have any questions or are there other things which are related to this topic that you would like to talk about?

Thank you for taking the time to discuss your experiences which will help in understanding the experiences of HIV infected women who have just had babies.

## APPENDIX 5: EXAMPLE OF FIELD NOTES

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### Field notes for participant 800-305-4

#### Interview conducted on 05 May 2011

##### Background summary information

The participant is 24 years old. She delivered her baby two weeks ago. She is married with three children, including the baby she has just delivered. She is HIV positive. She first tested positive when she was eight months pregnant with the recently delivered baby. Her previous HIV test was done three years ago, and she tested HIV negative. She delayed registering for ANC; she registered when she was 8 months pregnant. This interview was conducted to understand her reasons for the delay.

##### Interview arrangements

The participant met the study nurse and was recruited into the study on 03 May 2011. Because she sought ANC late she was asked to participate in the in-depth interview. Because I was not at the clinic on that day, an appointment for the 05 May 2011 was made. She came to the clinic for the interview on the appointed date. The interview was conducted in private, in one of the clinic rooms.

##### Reflections of methods and account

The interview was conducted according to the interview guide. To understand what the barriers were to seeking ANC on time, the strategy was to start with less personal questions, eg by first asking what she thought were barriers to registration for women in the community, before asking her what prevented her from seeking ANC on time. She quickly started to speak about the challenge that she faced in registering before we discussed the community challenges. She did not seem to feel uncomfortable discussing this. Throughout the interview she seemed to be open about her feelings and her fears.

The participant thinks ANC is very important, and she believes the community she comes from also believes the same. She delayed registering for ANC because she had no money. Before she registered she often worried about the delayed registration because she was often unwell. She did not seek treatment because she feared that the clinic visit would deplete the savings she was making towards the ANC registration fees. She also worried about the health of the baby given that she had heard stories of some babies dying in the womb without the mother knowing.

It was apparent from this interview that the participant feels very strongly that no one besides her husband should know about her HIV status. She feels that if people get to know one's HIV status they will spread the information around the community and they can even insult them.

The participant reports that at the six weeks visit she and her baby will be commenced on medicines. She says this is information that the nurses have given her; they have told her that

she and her baby both have to take some drugs. However she does not sound convincing that she got the information from the nurses, she sounds a bit hesitant when she says the information came from the nurses. It could be that this is information she gathered from other sources, eg listening to conversations among friends.

When asked why she thought some HIV positive people would not disclose their status to the nurses she said it may be because they are worried that the nurse may discuss their HIV care in the open, leading to other people getting to know of the HIV status. She narrated how she had the same fear (that her relatives would get to know her HIV status through the nurses). She however seems to believe very strongly that for the sake of the health of the mother and the baby, one should disclose her HIV status to the nurses.

### **Additional information**

At age six weeks the participant's baby was tested for HIV and tested HIV positive. Throughout the study there were instances where she revealed that she put a lot of effort in ensuring that the people around her did not find out about her HIV status. For example, if she was walking to the clinic in the company of her friends, she would not bring the remaining medicine (as requested by the study team) for the baby because she feared that her friends would find out about her HIV status.

### **Reflections on emerging themes**

#### *Importance attached to ANC registration*

- She thinks it is important to seek ANC.
- She thinks the community also values ANC

#### *No money for ANC registration*

- She clearly struggles to make ends meet
- Not seeking treatment even when she felt unwell (in an effort to save up for ANC registration)

### **STIGMA**

- *Fear of disclosing one's HIV positive status*
  - Friends and family may discriminate
  - Husband may leave you
- *Fear of stigma makes seeking the necessary HIV-related health care difficult*
  - Her own experience of this
  - As a possible explanation of why some women chose not to disclose their HIV status to the nurses

#### *Perceptions of community barriers to seeking ANC*

- No money for ANC fees
- Not willing to be tested for HIV (because of the fears given above for stigma)

*Appreciates the value of ARV prophylaxis in reducing chances of HIV transmission to the baby*

*Appropriate care given to the participant/baby*

- The participant reports that she got the required care to ensure prevention of HIV transmission to the baby (***however since she only started on the MER regimen at eight months or pregnancy, according to the Ministry of Health and Child Welfare guidelines the baby must have been given ARV prophylaxis for 28 days; but was only given for seven days***)

## **APPENDIX 6: EXAMPLE OF INTERVIEW SUMMARY**

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### **Interview Summary for participant 800-305-4 Interview conducted on 05 May 2011**

#### **BACKGROUND SUMMARY INFORMATION**

The participant is 24 years old. She delivered her baby two weeks ago. She is married with three children, including the baby she has just delivered. She is HIV positive. She first tested positive when she was eight months pregnant with the recently delivered baby. Her previous HIV test was done three years ago, and she tested HIV negative. She delayed registering for ANC; she registered when she was 8 months pregnant. This interview was conducted to understand her reasons for the delay.

#### **SUMMARY OF INTERVIEW**

The participant spoke openly and freely about her experiences and fears.

##### **Awareness of Importance of ANC**

The participant thinks ANC is very important, and she believes the community she comes from also believes the same. She believes ANC is important because the woman gets a chance to be tested for HIV, and if found positive, then appropriate PMTCT is given. She says it is also important because it ensures that the health status of the baby is monitored.

##### **Reasons for delayed ANC registration**

She delayed registering for ANC because she had no money. Before she registered she often worried about the delayed registration because she was often unwell (sickly). She did not seek treatment for her illnesses because she feared that the clinic visit would deplete the savings she was making towards the ANC registration fees. During this period (before she sought ANC), she also worried about the health of the baby given that she had heard stories of some babies dying in the womb without the mother knowing.

##### **Reasons why the people in the community do not seek ANC**

The participant reports that the main barrier is that people cannot afford the ANC registration fees.

The other barrier is that some women are afraid of getting tested for HIV. They are afraid because they suspect that they could be HIV positive. They think they could be HIV positive because they have seen their partners engaging in risky behaviour (having extra marital affairs). The participant says testing HIV positive could have some undesirable consequences for the woman: they could be discriminated against, and their husband could leave them. She says husbands can just leave, giving reasons that the woman has HIV and they have not, even though they may not have been tested themselves.



### Care that was given during and soon after pregnancy

The participant was tested for HIV at the time she registered for ANC, when she was eight months pregnant. She was given AZT for prophylaxis (information taken from the questionnaire at time of delivery). After delivery she and her baby were given ARV prophylaxis drugs for seven days.

### HIV-related care for the participant

The participant has not been examined to determine HIV disease progression. When asked what she is planning to do about her own HIV-related care, she revealed that she believed she will get some help (in the form of tablets) when she comes to the clinic for the six weeks visit. **[This actually is not the clinic procedure, women are referred to one of the hospitals where disease progression is assessed and appropriate treatment/advice given; one may not be given any drugs depending on how far the disease has progressed]** She said she got this information from the nurses. However she did not sound very positive when she said the nurses gave her this information. It could be that she assumed that since she and baby both got drugs soon after delivery, the same trend (of mother and child getting medicines) would continue at six weeks post-delivery (line 390-391). Or this could be a myth she could have picked up in discussions in the community, as suggested by line 393 where she said she just heard people saying.

### Disclosure of HIV status

The participant has not disclosed her HIV status to anyone but her husband. She says she does not want to disclose to any other people because she does not trust them to uphold confidentiality; she fears that this could be information that is spread around the community. She feels that when people know your HIV status they may tell you off using your HIV status (line 439-442). She fears that some people may say some hurtful things which will make her lose her peace of mind (line 437). She says she would rather endure the difficulties of being HIV positive on her own, and only disclose to relatives when she feels she can no longer bear it alone (line 444-447).

When she disclosed her HIV status to her husband, he at first did not accept it. He was quick to say that he is HIV negative and it cannot true that his wife is HIV negative. In the end the participant convinced him that they need to get tested together, he agreed, but by the time of the interview he had not yet been tested. The participant has been trying to implement some of the things she was taught at counselling, including practising safer sex. This is a challenge because the husband refuses to use condoms. He has said he would rather wait until the baby is old enough for them to have sex. It seems there is no agreement between them how old the baby should be when they start having sex again because she has already refused to have sex with him, citing the reason that the baby is still too small for them to do so (line 363-366). She is hoping that they will go for couple counselling, and that the counsellor will make him understand what needs to be done (line 365-366). The husband however has no problem with her adhering to drugs (or giving medicines to the baby).

### **Adherence to ARV prophylaxis drugs other teachings**

The participant had no problems adhering to her ARV prophylaxis drugs when she was pregnant. She also adhered to the times when giving the medicine to the baby. She said it was the first thing she wanted because she did not want to disadvantage the baby. She was taught to ensure exclusive breast feeding and she says she has no problem with that.

### **Participant's feelings about being HIV positive**

The participant was counselled when she was given the result. The counselling made it easier to accept the result at the time but when she got home she got distressed. She worried that she would die and leave her small children. She says with time she got better because she realised that she is not the only one who has HIV, and she also got additional counselling. She said the result did not surprise her because her husband had had an affair with a woman whom she suspected could have infected him.

### **Reasons why some HIV positive women do not disclose their status to the nurses**

The participant thinks some women do not disclose because they are worried that the nurses may discuss the HIV information in the presence of other people. This may result in friends and relatives finding out about the person's HIV status, which the woman fears may cause discrimination and unpleasant talk. She described that she felt this way at the time she was discharged from the clinic after delivery; there were people around who had come to take her home. She found it difficult to collect her ARV prophylaxis drugs because she did not want the people to find out about her HIV status.

Despite these fears the participant feels it is foolish not to disclose an HIV positive status to the nurses because one would then have failed to protect the baby and get appropriate care for oneself.

At the end of the interview, the participant asked a question about the risks of study participation that had been mentioned in the informed consent form. She was worried about a statement that other people may know about her participation in the study and assume that she is HIV positive, and potentially discriminate against her. She worried about whether the study team would openly discuss her HIV status when she came to the six weeks visit. She was reassured that the study staff would do the best to uphold confidentiality.

### **Reflections on emerging themes**

#### *Importance attached to ANC registration*

- She thinks it is very important to seek ANC
- She thinks the community also values ANC

#### *No money for ANC registration*

- She clearly struggles to make ends meet

- Not seeking treatment even when she felt unwell (in an effort to save up for ANC registration)
- Worrying about the baby's health during pregnancy (not knowing whether the baby was okay)

### **STIGMA**

- *Fear of disclosing one's HIV positive status*
  - Friends and family may discriminate or say hurtful things
  - Husband may leave you
- *Fear of stigma makes seeking the necessary HIV-related health care difficult*
  - Her own experience of this
  - As a possible explanation of why some women chose not to disclose their HIV status to the nurses
  - Some women may not get tested for HIV because they fear that they could be stigmatised if they test HIV positive
- Very strong desire to make sure that people do not find out about HIV positive status

### **Perceptions of community barriers to seeking ANC**

- No money for ANC fees
- Not willing to be tested for HIV (because of the fears given above for stigma)

### **Appreciates the value of ARV prophylaxis in reducing chances of HIV transmission to the baby**

- Motivated good adherence to times she was supposed to give the medicine to the baby

### **Appropriate care given to the participant/baby**

- Participant was tested for HIV time of ANC registration
- The participant feels that she got appropriate care (*however since she only started on the MER regimen at eight months, according to the Ministry of Health and Child Welfare guidelines the baby must have been given ARV prophylaxis for 28 days; but was only given for seven days*)

### **Role of husbands/partners in ensuring appropriate HIV prevention and management practices**

### **Inadequate/Incorrect information on the health care that is due to HIV infected people**

## APPENDIX 7: EXAMPLE OF ANALYTIC MEMO

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### Analytic Memo

#### Financial Challenges to ANC registration

This was the major reason that women gave for not having registered. Most participants reported that they had not registered because they could not afford the ANC fees. Indeed many women gave insightful accounts of how severely affected by poverty they were. For example participant 800-373- said after she had delivered she had to sell her bed to ensure that she got money that she could pay before the clinic would discharge her (the clinic does not discharge women from the clinic. Other women talked about how much they had longed to be registered (373 and), especially because they were often sick during the pregnancy. Participant 373 said she could not seek health care without having registered because she thought unregistered women were not accepted at the clinic. This supports the view by some participants that unregistered women are treated as if they do not belong to the clinic; they are not welcome at the clinic. Another participant, 305, talked about how she could not seek care because she feared she would deplete the savings she was trying to make towards the ANC fees.

On the other hand, is it not possible that some women just gave financial problems as reasons because it was easier to talk about? It could be that other reasons were seen as painting a bad picture about the participant (**eg could the participants have worried about being seen as unfit mothers?) Participant 800-312-1 could be one such participant, the bulk of whose interview showed that she thought of ANC registration as a way to get to a point, rather than a way into the process.**

**Reflexivity:** The study team were perceived of as health care workers with the same qualifications as the nurses (participants basically addressed then as Mbuya, the term that is used for addressing nurses at the clinic. Could it be because of this that participants may have found it harder to admit to things that are not encouraged by health care workers?

## APPENDIX 8: JOURNAL ARTICLE FOR THE SYSTEMATIC REVIEW

OPEN

# The magnitude of loss to follow-up of HIV-exposed infants along the prevention of mother-to-child HIV transmission continuum of care: a systematic review and meta-analysis

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**Introduction:** Although prevention of mother-to-child HIV transmission (PMTCT) programs are widely implemented, many children do not benefit from them because of loss to follow-up (LTFU). We conducted a systematic review to determine the magnitude of infant/baby LTFU along the PMTCT cascade.

**Methods:** Eligible publications reported infant LTFU outcomes from standard care PMTCT programs (not intervention studies) at any stage of the cascade. Literature searches were conducted in Medline, Embase, Web of Knowledge, CINAHL Plus, and Maternity and Infant Care. Extracted data included setting, methods of follow-up, PMTCT regimens, and proportion and timing of LTFU. For programs in sub-Saharan Africa, random-effects meta-analysis was done using Stata v10. Because of heterogeneity, predictive intervals (PrIs; approximate 95% confidence intervals of a future study based on extent of observed heterogeneity) were computed.

**Results:** A total of 826 papers were identified; 25 publications were eligible. Studies were published from 2001 to 2012 and were mostly from sub-Saharan Africa (three were from India, one from UK and one from Ireland). There was extensive heterogeneity in findings. Eight studies reported on LTFU of pregnant HIV-positive women between antenatal care (ANC) registration and delivery, which ranged from 10.9 to 68.1%, pooled proportion 49.08% [95% confidence interval (CI) 39.6–60.9%], and PrI 22.0–100%. Fourteen studies reported LTFU of infants within 3 months of delivery, range 4.8–75%, pooled proportion 33.9% (27.6–41.5), and PrI 15.4–74.2. Children were also lost after HIV testing; this was reported in five studies, pooled estimate 45.5% (35.9–57.6), PrI 18.7–100%. Programs that actively tracked defaulters had better retention outcomes.

**Conclusion:** There is unacceptable infant LTFU from PMTCT programs. Countries should incorporate defaulter-tracking as standard to improve retention.

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**Keywords:** HIV-exposed infants, loss to follow-up, meta-analysis, prevention of mother-to-child HIV transmission programs, retention, review, systematic

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2787



## Background

There have been significant developments in knowledge of interventions that can save lives of HIV-exposed infants. Current WHO guidelines recommend HIV testing of HIV-exposed infants at 4–6 weeks [1] postnatally (early infant diagnosis, EID), and immediate antiretroviral therapy (ART) initiation for those testing positive. As early cessation of breastfeeding is associated with poor health outcomes for HIV-exposed babies [2–6], current guidelines support continued breastfeeding in conjunction with extended infant prophylaxis with nevirapine (WHO option A) [7], and re-testing of the exposed baby at least 6 weeks after cessation of breastfeeding [1]. Also, included within the guidelines are recommendations for infant feeding in the context of HIV [5], which stress that carers need to be educated about the importance of exclusive breastfeeding in the first 6 months of life. All these guidelines necessitate continued follow-up of exposed babies to ensure their full participation in the postnatal care cascade. Yet despite advances in knowledge of effective interventions to save lives of HIV-exposed infants, many infants do not access the full package of services because of loss to follow-up (LTFU) [8–11]. There is literature on LTFU of infants in research settings, and also in real-life program settings. We conducted a systematic review in order to determine the magnitude of LTFU of HIV-exposed infants from real-life (nonresearch intervention) PMTCT programs, and to describe program characteristics associated with lower rates of infant LTFU in order to inform future program and policy development.

## Methods

Publications were eligible for inclusion if they reported on LTFU of HIV-exposed infants/children from usual care programs rather than from research studies/programs. Medline, Embase, Web of Knowledge, CINAHL Plus, and Maternity and Infant Care were searched.

### Search strategy

The research question was split into three components: children/infants, HIV exposure, and retention/LTFU. For each component, text and Medical Subject Heading (MeSH) searches were performed. The text search terms for the children/infants component were as follows: Child\* OR infant\* OR newborn OR baby OR babies. The terms for HIV exposure were as follows: “HIV exposed or HIV positive adj3 mother\*” OR “HIV infected adj3 mother\*” OR “born adj3 HIV positive wom#n” OR “born adj3 HIV infected wom#n” OR PMTCT OR “prevention of mother to child transmission”. The terms for retention/LTFU were as follows: “continuum of care” OR retention OR attrition OR “patient dropout” OR “los? to follow up” OR LTFU

OR LFU OR “lost follow up” OR “Early infant diagnosis” OR EID. Results from the three components were narrowed to include only publications that featured all three components. The search process was iterative: pilot searches were conducted and checks for suitability of search terms were conducted. Refinements were made and the final search was conducted on 06 August 2012.

### Selection of eligible papers and additional searches

Results from database searches were combined and duplicates removed. Each title and abstract was reviewed to determine eligibility. A paper was rejected if it was obvious from title/abstract review that it was ineligible. When it was less clear, the full paper was reviewed. Next, reference and citation lists of eligible papers and those of other relevant papers were downloaded from the Web of Knowledge database and reviewed for eligibility. Eligibility review was conducted by E.L.S. Each eligible publication was assessed for quality using a checklist that was adapted from the UK National Institute for Health and Clinical Excellence (NICE) methodology checklist for cohort studies [12]. For each study, an overall subjective judgment was made on how well the study findings were protected against bias and confounding.

### Data extraction and synthesis

Information captured using a data collection form included place of study, setting (urban or rural), program years, testing strategy (whether opt-in or opt-out), schedule and methods of infant follow-up, prevention of mother-to-child HIV transmission (PMTCT) regimens offered, whether replacement feeding was offered for free during the years studied, and magnitude and timing of LTFU.

Study findings were split into categories relating to timing of LTFU as follows: LTFU of pregnant HIV-positive women between ANC registration and delivery; LTFU of HIV-exposed infants by age 3 months; LTFU of HIV-exposed infants by 12 months of age; LTFU by 18 months of age, and LTFU of infants after determination of HIV status. For studies in sub-Saharan Africa, random-effects meta-analysis using the method of DerSimonian and Laird [13] was conducted for each category/timing of LTFU using Stata v10. Data values were log-transformed before analysis and the results back-transformed to percentages. There was extensive heterogeneity of study findings; therefore, predictive intervals (PrIs; approximate 95% confidence intervals of a future study based on the observed heterogeneity) were computed as recommended good practice in the presence of significant heterogeneity [14]. To investigate the sources of heterogeneity, random-effects meta-regression analysis [15] was done with each of the extracted variables that were suspected to explain the heterogeneity: setting (urban/rural); model for offering HIV testing; mother's PMTCT regimen (single dose nevirapine vs. more



intensive regimens); and whether replacement feeding was offered for free during program years.

## Results

A total of 826 papers from database and reference/citation lists were reviewed (Fig. 1a). Eighteen eligible papers were identified from database searches, and an additional seven were identified after reviewing reference and citation lists, bringing the total of eligible papers from which data were extracted to 25, (Fig. 1b).

### Description of eligible papers

Twenty studies were from sub-Saharan Africa: four [16–19] from South Africa, two each from Kenya [20,21], Nigeria [22,23], Mozambique [24,25], Malawi [26,27], Uganda [28,29], and Ethiopia [30,31], one from each of the following: Zimbabwe [32], Cameroon [33], Angola [34], and Tanzania [35]. Three studies were from India [36–38], and one each from United Kingdom and Ireland [39,40]. All were viewed to be either of good (17 studies) or fair (eight studies) quality [12]; as a result, they were all included in result syntheses as applicable. Seven studies were set in rural areas, 14 in urban areas, and three included both urban and rural sites. The PMTCT regimen provided for mothers during the study period was single dose nevirapine for nine studies and was more intensive (dual/triple therapy) for 13 studies (Table 1).

### Loss to follow-up of HIV-positive pregnant women

Eight studies reported on LTFU of HIV-positive pregnant women between ANC registration and delivery. Six of these were in sub-Saharan Africa and two from India. The percentage LTFU in these eight studies ranged from 10.9 to 68.1%. The lowest proportion of 10.9% was reported in Maharashtra, India, a private sector PMTCT program in which women who missed their appointments were followed up by letter, phone calls, or home visits [37]. The pooled estimate of LTFU among the six sub-Saharan African countries was 49.08% (95% confidence interval 39.6–60.9%; PrI 22.0–100% (Fig. 2)).

On meta-regression analysis, only the type of PMTCT regimen (whether single dose nevirapine or more intensive regimens) was also associated with LTFU; there was higher LTFU in the sites that offered single dose nevirapine than in those that offered more intensive regimens ( $P=0.006$ ). However, this did not account for all heterogeneity; there was 92% residual heterogeneity.

### Loss to follow-up of infants by age 3 months

Fourteen studies reported on LTFU of infants soon after delivery; the infants typically did not return for HIV

testing at 6 weeks. About half of the studies reported this as LTFU at 6 weeks, but some studies reported loss by 8 weeks, or 3 months. In order to synthesize data from all studies that reported LTFU soon after delivery, a cut-off point of 3 months was reported. The percentage LTFU by age 3 months in the 14 studies ranged from 4.1 to 75.0%. The LTFU percentages in the studies in Ireland, UK, and India were 4.1, 26.0, and 19.6, respectively. The pooled estimate among 11 sub-Saharan African countries was 33.9% (27.6–41.5), PrI 15.4–74.2 (Fig. 3).

The lowest LTFU percentages were reported in Ireland and Malawi. In Ireland, there was a system for follow-up of HIV-exposed infants, which was enhanced by having a single center for the coordination of care of HIV-exposed infants. However, although the study in Malawi [26] reported low LTFU rates at 6 weeks, by the 6-month postnatal visit 41% of infants had been lost; the babies were initiated on cotrimoxazole prophylaxis, but were lost from further evaluation. In that study all PMTCT services were centrally provided at the hospital during the reported period. This is one example in which centralization of PMTCT services may not have worked well: authors reported that women may have increasingly found it more difficult to come back to the hospital because of long distances in an area where there was no public transport (women had to either walk or use bicycles) and would, therefore, have benefited from decentralized services at local clinics. The program in Cameroon [33] tracked clients using mobile phones; 90% of clients had mobile phones. This tracking may have improved their LTFU rates as they had comparatively lower LTFU rates than other sites of 17%. There was also good tracking of defaulters in the UK study in London [39], which reported a LTFU of 26%. Of note, the majority of infants lost to follow-up in that program were born to African mothers, 89% compared with 71% of those who completed follow-up.

Both Mozambican studies reported LTFU rates of about 75%, in a setting in which there was lack of confidential counseling for women in crowded postnatal wards. The authors reported that this environment may have resulted in HIV-positive women feeling uncomfortable, thereby lessening their chances of returning to the hospital for the baby's EID. In addition, authors reported that the provision of EID services occurred in a different building from the one where referral was made possibly resulting in women getting lost between referral and follow-up. Related to this, in one of the studies from Ethiopia [30] some infants who had defaulted from EID had been to a healthcare center for pentavalent vaccination at 6 weeks: 86% of infants were brought for pentavalent vaccine compared with 52% for EID.

In meta-regression analysis, none of the variables extracted from the studies explained the heterogeneity in LTFU findings by age 3 months.

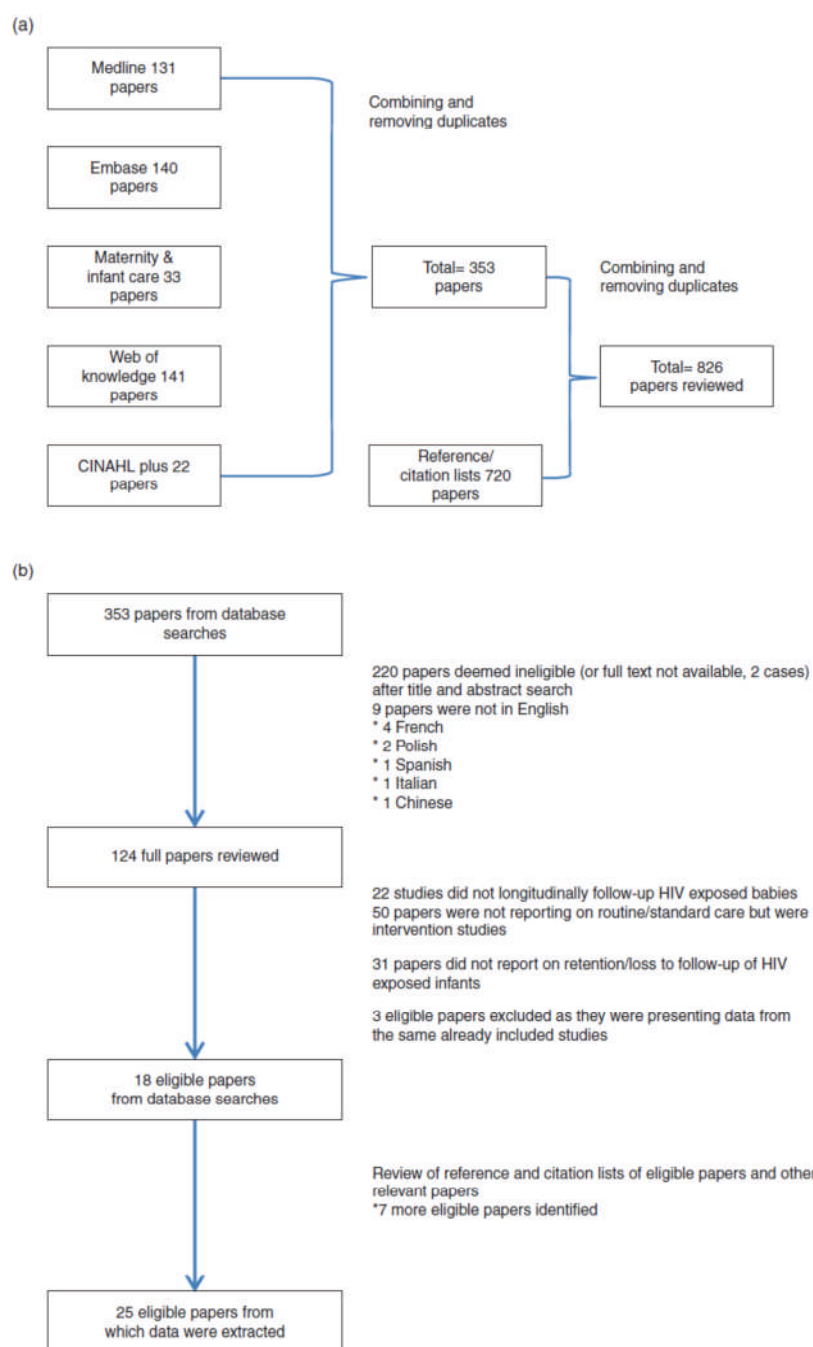


Fig. 1. Literature search results and selection of eligible papers. (a) Results of literature searches. (b) Selection of eligible papers.



Table 1. Description of eligible studies.

Author	City and country	Program years	Setting	Testing strategy	Mother's PMTCT regimen	Infant follow-up schedule	LTFU outcome/s reported	LTFU n/N (%)
Sam <i>et al.</i> [39]	London, United Kingdom	1992–2001	Urban	Not reported	Not reported	Infant follow-up visits, including HIV testing.	Infants LTFU before determination of HIV status by 3 months	27/104 (26.0)
Ferguson <i>et al.</i> [40]	Ireland	1999–2008	-	Opt-out	HAART or triple therapy	All exposed infants referred to one clinic for management	Infants LTFU before 3 months of age	40/964 (4.1)
Ahoua <i>et al.</i> [28]	Arua, Uganda	2000–2005	Rural	Opt-in	HAART or dual therapy	Infant follow-up at 1, 6, 10 and 14 weeks, then every 3 months until HIV test at 18 months	1) HIV-positive women LTFU between ANC registration and delivery	520/1037 (50.1)
Sherman <i>et al.</i> [19]	Johannesburg, South Africa	2001–2001	Urban	Not reported	Single dose nevirapine	Infant follow-up: HIV testing using ELISA at 12 months	2) Infants LTFU at 18 months	303/567 (53.4)
Perez <i>et al.</i> [32]	Buhera Zimbabwe	2001–2003	Semi-rural	Opt-in	Single dose nevirapine	Monthly for growth monitoring; baby tested at 15 months	Infants who did not return for testing at 12 months	57/67 (85.1)
Doherty <i>et al.</i> [17]	Nine provinces, South Africa	2002	Rural and urban	Opt-in (mostly)	Single dose nevirapine	HIV test using rapid tests at 12 months; re-testing at 18 months if positive	LTFU of HIV-positive women between ANC registration and delivery	167/326 (51.2)
Manzi <i>et al.</i> [26]	Thyolo District Malawi	2002–2003	Rural	Opt-out	Single dose nevirapine	HIV test using rapid tests at 12 months; re-testing at 18 months if positive	Infants who did not return for HIV testing at 12 months	958/1907 (50.2)
Moses <i>et al.</i> [27]	Lilongwe Malawi	2002–2006	Urban	Opt-in until 2005	Single dose nevirapine	Follow-up according to EPI schedule up to 18 months. HIV test at 18 months	1) HIV-positive women LTFU between ANC registration and delivery	440/646 (68.1)
Oladokun <i>et al.</i> [23]	Ibadan Nigeria	2002–2007	Urban	Opt-in since 2005	Single dose nevirapine until 2005	BID using DNA PCR at 6 weeks	2) Infants LTFU by 6-week postnatal visit	10/206 (4.9)
Panditrao <i>et al.</i> [37]	Maharashtra India	2002–2008	Urban and rural	Not reported	Dual therapy	BID using DNA PCR at 6 weeks	Infants who did not return for HIV testing at 6 weeks	207/03160 (65.5)
Black <i>et al.</i> [16]	Johannesburg South Africa	2004–2007	Urban	Not reported	HAART	BID using DNA PCR	1) Babies who did not return for HIV testing at 18 months	63/303 (20.8)
Geddes <i>et al.</i> [18]	Durban, South Africa	2004–2007	Urban	Opt-out since 2006	HAART or dual/triple therapy	BID using DNA PCR at 6 weeks	2) Babies whose HIV test results were not collected	88/207 (42.5)
Goswami and Chakravorty [36]	Kolkata India	2004–2007	Urban	Opt-in	Single dose nevirapine	EID at HIV clinic; HIV-positive infants followed at same clinic	1) HIV-positive women LTFU between ANC registration and delivery	80/733 (10.9)
Nuvagaba-Biribomwoha <i>et al.</i> [35]	Lake region, Tanzania	2006–2007	-	Not reported	Single dose nevirapine	Follow-up in pediatric clinic of hospital; HIV test using ELISA at 18 months	2) Infants who did not return for HIV testing at 6 weeks	151/770 (19.6)
Azcoaga-Lorenzo <i>et al.</i> [20]	Busia District Kenya	2006–2008	Rural	Opt-out	HAART or dual therapy	EID at HIV clinic; HIV-positive infants followed at same clinic	Infants who did not return for HIV testing at 6 weeks	128/699 (18.3)
Hassan <i>et al.</i> [21]	Kilifi, Kenya	2006–2008	Rural	Opt-out	Not reported	Follow-up in pediatric clinic of hospital; HIV test using ELISA at 18 months	1) HIV-positive women LTFU between ANC registration and delivery	113/248 (45.6)
							2) Babies who did not return for testing at 18 months	36/95 (37.9)
							1) Infants whose EID HIV PCR results were not collected after testing (both positive and negative infants)	199/441 (45.1)
							2) HIV-positive infants whose EID results were not collected after testing	24/75 (32)
							1) HIV-positive women LTFU between ANC registration and delivery	632/1668 (37.9)
							2) Infants LTFU before determination of HIV status at 6 weeks	148 (19.3)
							1) Infants lost before determination of HIV status at 18 months	119/180 (66.1)
							2) Infants whose HIV test results were not collected	46/102 (45.1)

Table 1 (continued)

Author	City and country	Program years	Setting	Testing strategy	Mother's PMTCT regimen	Infant follow-up schedule	LTFU outcome/s reported	LTFU n/N (%)
Seth <i>et al.</i> [38]	New Delhi, India	2006–2010	Urban	Not reported	Single dose nevirapine	All exposed infants followed up until 18 months. HIV-positive infants are put on HAART and followed further	LTFU of babies before determination of HIV status at 18 months	47/162 (29.0)
Cook <i>et al.</i> [25]	Zambézia Province, Mozambique	2007–2008	Rural	Opt-out	HAART or dual therapy	Infants referred to 'child at risk' clinics. EID using PCR test	Infants who did not come back for EID	333/443 (75.2)
Anojie <i>et al.</i> [22]	South-South region, Nigeria	2007–2009	Rural and urban	Not reported	HAART or dual therapy	EID at 6 weeks; if negative, re-test 6 weeks after cessation of breast feeding	HIV-positive infants LTFU after testing (EID), not enrolled in ART program	85/125 (68)
Namukwaya <i>et al.</i> [29]	Kampala, Uganda	2007–2009	Urban	Not reported	HAART or dual therapy	Infant testing by PCR at 6 weeks	1) HIV-positive women LTFU between ANC registration and delivery 2) Infants who did not return for HIV testing by 3 months	313/47941 (39.5) 244/24807 (50.8)
Lussiana <i>et al.</i> [34]	Luanda, Angola	2007–2011	Urban	Not reported	HAART	Monthly follow-up; HIV test at 9, 12, and 18 months using rapid tests	1) LTFU of HIV-positive women between ANC registration and delivery 2) Infants not returning for hospital evaluations after delivery	164/382 (42.9) 42/218 (19.3)
Shargie <i>et al.</i> [31]	Addis Ababa, Ethiopia	2008–2009	Urban	Not reported	HAART or dual/triple therapy	EID at 6 weeks; follow-up for cotrimoxazole prophylaxis	LTFU of infants during follow-up period after EID	36/118 (30.5)
Nlend <i>et al.</i> [33]	Yaounde, Cameroon	2008–2010	Urban	Opt-out	HAART or dual therapy	EID at 6 weeks; done at referral center	Infants who did not return for HIV testing at 6–8 weeks	103/587 (17.5)
Mirkuzie <i>et al.</i> [30]	Addis Ababa, Ethiopia	2009	Urban	Not reported	HAART or dual/triple therapy	HIV test at 6 weeks; monthly follow-up until 6 months, then every 3 months until 18 months	Infants who did not return for HIV testing at 6 weeks	106/221 (48.0)
Ciampa <i>et al.</i> [24]	Zambézia Province, Mozambique	2009–2010	Rural	Opt-out	HAART or dual therapy	HIV testing using PCR at 1 month	Infants who did not return for HIV testing by age 3 months	247/332 (74.4)

EID, early infant diagnosis; LTFU, loss to follow-up; PMTCT, prevention of mother-to-child HIV transmission.

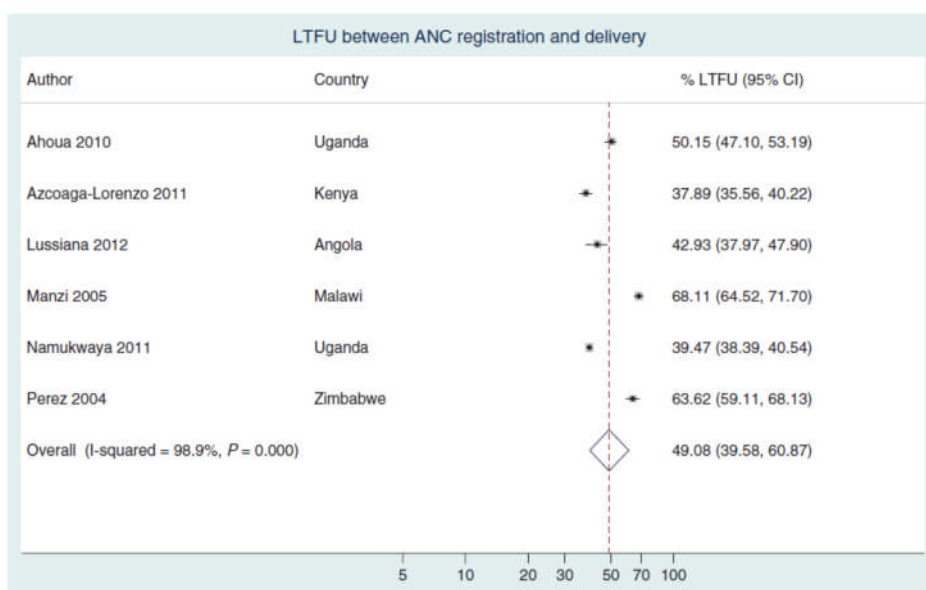


Fig. 2. Loss to follow-up of HIV-positive pregnant women between ANC registration and delivery. CI, confidence interval; LTFU, loss to follow-up.

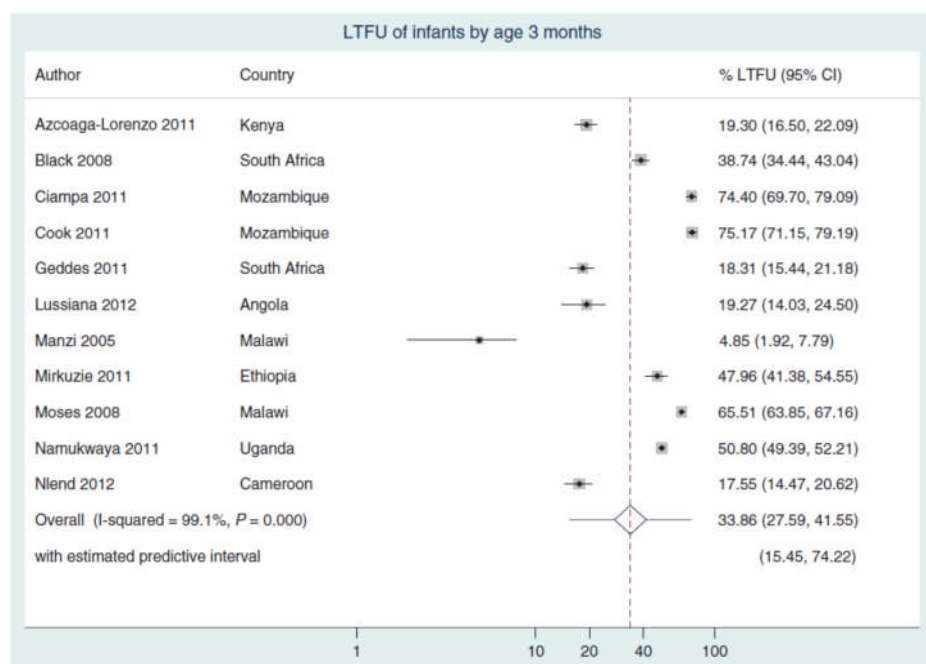


Fig. 3. Loss to follow-up of infants by age 3 months. CI, confidence interval; LTFU, loss to follow-up.



### Loss to follow-up of infants at 12 and 18 months

Two studies (both from South Africa) reported on LTFU of infants after 12 months. The studies reported losses of 85.1 and 50.2%, respectively. Both programs offered single dose nevirapine.

Five programs, three of which offered single dose nevirapine, reported on LTFU of infants by 18 months. Two were from India, with LTFU percentages of 37.9 and 29, and one each from Uganda (53.4%), Kenya (66.1%), and Nigeria (20.8%).

### Loss to follow-up of infants after HIV testing

Five studies (all from Sub-Saharan Africa) reported on LTFU of infants following HIV testing, mostly EID by PCR: infants were lost during the recommended follow-up period after receipt of HIV results at about 45 days (one study) [31], did not enrol into ART programs after testing HIV positive in the EID program (one study) [22], or did not return to collect HIV test results after EID (two studies) [21,35]. The percentage LTFU after testing ranged from 30.5 to 68.0%, pooled estimate, 45.5% (35.9–57.6), and PrI 18.7–100%.

Again the benefit of active follow-up of defaulters was apparent in the study in Tanzania [35], where the program actively tracked HIV-positive infants who had not returned to collect results. As a result, a lower percentage LTFU of 32% among HIV-positive infants was observed compared with 48% among the HIV-negative infants.

## Discussion

This systematic review revealed that there is an unacceptable LTFU of HIV-exposed infants at several points in the PMTCT care cascade in the programs reported here. There was significant heterogeneity in the study findings; pooled estimates were reported together with PrIs to indicate the uncertainty in the estimates. An estimated 49% of HIV-positive pregnant women in Sub-Saharan Africa are lost between ANC registration and delivery, whereas about 34% of infants are lost to follow-up by 3 months. A further 45% of infants are lost after HIV testing.

Of importance, the retention in a program is not necessarily equivalent to retention in the healthcare system; those women who have self-transferred out of a program to another facility should not be regarded as lost to follow-up. In this review, a third of programs either actively sought but did not find evidence of women self-transferring to other neighboring health sites or provided the only PMTCT services in the communities in which they operated. Four studies [16,24,25,39] acknowledged the possibility of migration being misclassified as LTFU

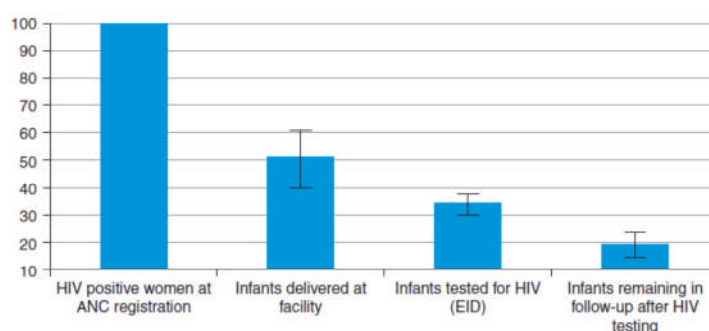
and the rest of the studies did not discuss this kind of LTFU.

If a woman is LTFU before delivery, she may not take her intrapartum antiretroviral prophylaxis and her baby is unlikely to be initiated on the necessary prophylaxis after delivery, and may not be registered for regular follow-up in the PMTCT program. For the mother, LTFU can result in delayed evaluation for disease progression and initiation of life-saving ART. In this systematic review, we found that programs that had an effective system for tracking defaulters had better retention outcomes suggesting that programmers should consider incorporating interventions to actively track women who have missed their appointments. It is important that tracking methods be appropriate for the setting. For example, the program in Uganda [29] had a high LTFU of 40% despite having a telephone tracking system because only 50% of clients had telephone contacts. Tracking requires resources, and depending on the setting and methods used can be expensive. Clearly, data on the relative costs and benefits of introducing such follow-up activities are required. There are other interventions that have been found to improve retention, for example, provision of confidential counseling space postpartum and direct accompaniment of mothers to the centers where continued care will be accessed from [24,41]. However, some have not been assessed as part of routine care, so the extent to which they would translate is unclear. Our search strategy was not designed to find all interventions that improve retention; we described nonresearch interventions that were found to be effective in programs that reported infant LTFU.

Of importance is the observation that even with active tracking of defaulters, there are still unacceptably high levels of LTFU along the PMTCT cascade, suggesting that other barriers need to be overcome. Qualitative studies have found that the following factors affect uptake of PMTCT services: fear of involuntary disclosure of HIV status, fear of stigma, disbelief of mother's HIV result, distance from health facility, fear of HIV-positive result for the baby, cultural norms, cost of transport, and unfriendly healthcare workers [42–49]. These challenges need to be addressed so that programs offer acceptable, culturally sensitive services that will attract all intended beneficiaries.

That cultural norms play a significant part in retention along the PMTCT cascade may be further evidenced by the fact that the majority of infants who were LTFU in the program in London were born of African mothers; their reasons for dropping out of care may be similar to the barriers reported in African settings, where LTFU rates are highest, but may also be due to concerns about immigration status. There is evidence from Cote d'Ivoire that economically disadvantaged women find it more difficult to participate in PMTCT programs [50],





**Fig. 4.** Simulation of cumulative loss to follow-up of exposed infants along prevention of mother-to-child HIV transmission cascade. EID, early infant diagnosis.

suggesting the need for structural interventions to promote retention.

Another program characteristic that was found to be associated with LTFU was the type of antiretroviral prophylaxis regimen offered; programs that offered single dose nevirapine had higher rates of LTFU than those that offered more intensive regimens. Single dose nevirapine was used in earlier programs than dual/triple prophylaxis, when programs were in the learning stages of how best to provide PMTCT services. In addition, dual/triple therapy necessitates more visits for prescription refills, exposing the woman to more intensive support, which may increase understanding of importance of PMTCT, acceptance of HIV status, and client's connectedness with the healthcare system. The recent introduction of the WHO Option B+ program, in which all HIV-positive pregnant/lactating women are given antiretroviral drugs, which are continued for life may help increase retention rates. Results from the Malawian Option B+ program indicate encouraging retention of 77% after 12 months of the program [51].

WHO has recommended that integrating child health services with PMTCT will likely improve infant retention in care [52]. In one of the Ethiopian programs reviewed here [30], infants who had been lost from the PMTCT program at 6 weeks had in fact been retained within the child health program (as evidenced by receipt of pentavalent vaccine at 6 weeks postnatally). Integration of these two services may have reduced LTFU in the PMTCT program. Importantly, integration should ensure confidentiality is maintained; fear of involuntary disclosure is a recurring theme in qualitative studies exploring barriers to continued attendance of HIV-related care visits. The two programs in Mozambique had very high levels of LTFU of 75%, which the authors partly attributed to lack of confidential counseling space.

If we simulate a cumulative LTFU cascade using data obtained in this systematic review for sub-Saharan

African countries, we will see that out of 100 HIV-positive pregnant women who are enrolled into a PMTCT program, only 19 infants are retained in care following HIV testing, (Fig. 4).

The strength of this systematic review is that it synthesizes real-life data from PMTCT programs. It provides a picture of how routine services function. Although studies were observational, they were generally of reasonable quality and did not suffer from significant bias in measurement of LTFU outcomes.

There was significant heterogeneity in the study findings, with very wide P<sub>ris</sub>. The main limitation of this review was our inability to fully explore the causes of heterogeneity. Another limitation of the review is that it did not include gray literature, which is likely to have had some reports from routine programs. This is a trade-off that was made by preferring peer-reviewed publications that were considered to have been more rigorously reviewed.

In conclusion, there are unacceptably high levels of LTFU of HIV-exposed infants at important points of the PMTCT cascade. Effective tracking of defaulters reduces LTFU; programmers should initiate effective interventions for tracking defaulting clients. In addition, each PMTCT site should investigate the patient-level factors that limit adherence to visit schedules and address them in a culturally sensitive and appropriate way.

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E.L.S., I.V.D.W., J.G.H. and F.M.C. conceived and designed the study. E.L.S. collected and analyzed data. E.L.S., I.V.D.W., J.G.H. and F.M.C. contributed to analysis. E.L.S. wrote first draft. E.L.S., I.V.D.W., J.G.H. and F.M.C. gave significant intellectual contribution to



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# Conflicts of interest

No conflicts of interest are declared.

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